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Acquired Brain Injury:

The lived experience of family members

Mark Holloway DipSW MA

A thesis submitted for the degree of Professional Doctorate in Social Work
University of Sussex;
March 2017

Statement

I hereby declare that this thesis has not been and will not be, submitted in whole or in part to another University for the award of any other degree.

Signature:.....

Acknowledgements:

If completed fully, the acknowledgements section of a professional doctorate that is undertaken after 25 years of work in the field has the potential to be longer than the thesis itself. It is not an exaggeration to say that there have been hundreds if not thousands of people who have sparked my interest, taught, trained, supervised, frustrated and encouraged me, pointed me in the right direction, given me ideas, challenged my views, given me something to fight against, given me something to fight for and so brought me to the University of Sussex to undertake this work. Such an endeavour is therefore most definitely a joint effort although the mistakes must remain only mine.

I have lost count of the numbers of people with brain injuries and their family members who have opened their doors to me, who have permitted me a glimpse of their lives, their lowest and their highest points. Each has a story that is worthy of telling, each teaches (and learns) as they tell, creating personal truth in hope from the chaos and trauma that such injuries most often bring. Each has played a part in my learning, professionally and, perhaps much more importantly for me, personally.

All of my colleagues at Head First have helped me with their support, their selfless sharing of knowledge and their time. Other people's ceaseless and loving belief can be sustaining when one's own belief waivers. My colleague Janine Heritage has held me up at times when it would have been easier for me to fall. My colleagues Emma Hay and Claire Dowle have provided peerless administrative support. I have been afforded all sorts of resources, without this generosity this research could not have taken place. I am fully aware of the debt of gratitude owed and shall not forget it.

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I am deeply indebted to the 110 people who completed my online survey, providing me with so much personal information and even more so to the 16 individuals who agreed to meet with me to tell me about their worst moments. These were people who were unafraid to share horror and hope as well as hate but mostly love, doing this despite the impact that this had upon them, doing this selflessly because they wanted other people to have a better experience.

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Dedication

To Jo Clark Wilson for the relentless and lifelong pursuit of other people's well-being, for doing this quietly and without ego, for sharing, for establishing the safest of havens and for knowing that each of us can only do what we can do.

The true meaning of life is to plant trees, under whose shade you do not expect to sit.

(Nelson Henderson)

And in loving memory of AJM, AG, PO'C and IF.

Thesis Abstract

UNIVERSITY OF SUSSEX

MARK HOLLOWAY

DSW

Acquired Brain Injury: The lived experience of family members.

Thesis Abstract:

Family members are themselves affected by the impact of Acquired Brain Injury (ABI) upon their relatives and they play an important role in the rehabilitation and long term support required. The study aims to understand how families are impacted and their views on the formal and informal support received directly or indirectly as a consequence of the ABI. To date there has been very little research undertaken by social workers in relation to ABI and/or the experience of family members.

A mixed methods research design was employed to capture the lived experience of family members of people with ABI. The results of the quantitative and qualitative data were triangulated against the literature.

An online survey was completed by 110 relatives of people with an ABI, seeking their experience of the condition, its impact upon their lives and their views of services. The results of the survey were collated and organised in SPSS (version 24). Non-parametric Spearman's Rho Correlations (non-parametric test) were performed upon the results. In-depth, semi-structured interviews were conducted with 16 family members of people with severe ABI to ascertain the family members' experience of their relatives' condition, its impact upon them and their views of the associated formal and informal support received. Inductive thematic analysis of the transcribed interview data was undertaken to identify themes.

The quantitative element of the research identified strong correlations between the relative's assessment of the invisible impairments suffered by those with an ABI (cognitive, executive, behavioural and emotional difficulties) and lack of insight. This

correlation was not present in relation to physical impairment. It was observed that increased loss of insight and behavioural difficulties were strongly correlated with loss of friendships by the non-injured family member. The results of the inductive thematic analysis identified 7 themes which were:

- 1: The Context
- 2: The All-Encompassing Challenge
- 3: Family Loss and Grief
- 4: The Unavoidable Burden
- 5: The Poor Experience of Support
- 6: Positive Support and Change
- 7: The Curator of Narrative

The research identified that family members' experience is complex and enduring, encompassing most aspects of life, and is affected by the context in which it occurs as well as by formal and informal support structures. The particular nature of the grief and loss experienced by families is ambiguous, develops over time and leads to ambivalent feelings for family members who perceive no option but to remain involved. Informal and formal support frequently fails to take account of the reality and complexity of the condition and fails to integrate the relative by recognising their own losses and trauma. Relatives' views on the services received identified significant gaps in practitioner knowledge, most especially of those aspects of life that were of most concern to them, the invisible impairments and issues with insight. Practitioners that were valued were more likely to be specialists in the condition and practiced as "expert companions" supporting the relative to develop a new "neuro-narrative" to reconstruct their identity in the face of their ongoing grief. The specific nature of the condition requires such an approach if input is to be effective.

Greater understanding of the complex lived experience of family members may support more effective responses to both them and the individual with ABI, integrating services and families to improve quality-of-life. As ABI is a process with changes to functioning developing over time, the information and knowledge required by loving

and supportive relatives needs to be created with them, being person-, family-, injury- and context-specific.

Table of contents:

Chapter 1: Introduction	1
<i>1.1: My background and interest:</i>	2
<i>1.2: Prevalence of Acquired Brain Injury in the UK:</i>	4
<i>1.3: Aims:</i>	6
<i>1.4: Objectives:</i>	7
<i>1.5: Research Questions</i>	7
<i>1.6: Structure of the thesis</i>	8
 Chapter 2: Literature Review	 11
<i>2.1: Search Methods</i>	12
<i>2.2: Search 1 Literature relating to social work and ABI</i>	13
<i>Social Work and Brain Injury, The academic evidence</i>	17
<i>2.3: Literature Search 2:</i>	20
<i>Impact of Acquired Brain Injury on the individual</i>	20
<i>Impact of Acquired Brain Injury: Loss of Insight</i>	24
<i>Impact of Acquired Brain Injury: Loss of self, enforced identity change</i>	27
<i>Impact of ABI: Functional outcomes for the injured party</i>	31
<i>2.4: Literature Search 3:</i>	35
<i>Impact of acquired brain injury: The Family</i>	35
<i>Impact of ABI: The role of the family in support, care and rehabilitation</i>	38
<i>2.5: Literature search conclusion</i>	39

Chapter 3: Methodology and Methods.....	41
<i>3.1: Methodological Position</i>	<i>41</i>
<i>3.2: The dominance of positivism in the “neuro”-world</i>	<i>43</i>
<i>3.3 Study design</i>	<i>49</i>
<i>3.4: Online Survey</i>	<i>52</i>
<i>3.5: Recruitment: Online Survey</i>	<i>55</i>
<i>3.6: Data Collection, online survey responses</i>	<i>55</i>
<i>3.7: In-Depth Semi-Structured Interviews</i>	<i>56</i>
<i>3.8: Interview sample size</i>	<i>56</i>
<i>3.9: Choosing the interviewees</i>	<i>58</i>
<i>3.10: Logistics</i>	<i>60</i>
<i>3.11: The Interviews</i>	<i>61</i>
<i>3.12: Ethics</i>	<i>61</i>
<i>3.13: Researcher positioning and reflexivity</i>	<i>64</i>
<i>3.14: Ethics in Practice</i>	<i>68</i>
<i>3.15: Data Analysis</i>	<i>71</i>
<i>3.16: Identification of themes</i>	<i>75</i>
<i>3.17: Overall Analysis: integration of literature, quantitative results and inductively derived themes</i>	<i>77</i>
Chapter 4: Online Survey: Analysis and Findings	79
<i>4.1: Results – Respondent descriptors</i>	<i>79</i>
<i>4.2: Results – descriptors of the brain injured party (PwBI)</i>	<i>80</i>
<i>4.3: Results – Respondent rating of difficulties as a consequence of the ABI</i>	<i>83</i>
<i>4.4: Results: Commentary and narratives from the online survey</i>	<i>89</i>

Chapter 5: The Interviews: Findings and Analysis.....	109
<i>5.1: Anonymity and coding</i>	<i>109</i>
<i>5.2: The Themes</i>	<i>111</i>
<i>5.3.1: Theme 1: The Context</i>	<i>113</i>
<i>5.3.2: Theme 2: The All-Encompassing Challenge</i>	<i>117</i>
<i>5.3.3: Theme 3: Family Loss and Grief</i>	<i>124</i>
<i>5.3.4: Theme 4: The Unavoidable Burden</i>	<i>136</i>
<i>5.3.5 Theme 5: The Poor Experience of Support</i>	<i>148</i>
<i>5.3.6: Theme 6: Positive Support and Change</i>	<i>159</i>
<i>5.4: Theme 7: The Curator of Narrative</i>	<i>172</i>
Chapter 6: Discussion: Research Synthesis and Recommendations	179
<i>6.1: Ambiguous Loss, Information, Knowledge and the Provision of Prognoses</i>	<i>179</i>
<i>6.2: The shared if different experience of relatives and people with ABI</i>	<i>186</i>
<i>6.3: The role of the “Expert Companion” for the relative’s transformative journey</i>	<i>191</i>
<i>6.4: Limitations of this Study</i>	<i>200</i>
<i>6.5: Recommendations for Practice</i>	<i>202</i>
Chapter 7: Conclusion.....	206
References	211

Tables:

Table 1: <i>Gender of respondent</i>	79
Table 2: <i>Age of respondent</i>	79
Table 3: <i>Relationship of respondent to the PwBI</i>	80
Table 4: <i>Gender of PwBI</i>	80
Table 5: <i>PwBI age at time of injury</i>	80
Table 6: <i>Cause of injury: Trauma vs Non-Trauma</i>	81
Table 7: <i>Cause of injury: Mechanism of ABI</i>	81
Table 8: <i>PwBI living status: Community vs Non-Community setting</i>	81
Table 9: <i>Years since injury</i>	82
Table 10: <i>PwBI Living Status: Type of accommodation</i>	82
Table 11: <i>PwBI employment status</i>	83
Table 12: <i>Frequency of report by domain of difficulty</i>	84
Table 13: <i>Correlations between domain of difficulty and reduced insight</i>	85
Table 14: <i>Rate of post injury friendships for both the PwBI and respondent</i>	86
Table 15: <i>Correlations between domain of difficulty and reduced friendships for the respondent</i>	87
Table 16: <i>Respondent rating of the services received by the brain injured party as a consequence of the brain injury</i>	88
Table 17: <i>Key to support identify respondent/PwBI details</i>	90
Table 18: <i>Anonymised information regarding participants and individual codes to aid identity</i>	110
Table 19: <i>The Themes: Construction and Connections</i>	178
Table 20: <i>Characteristics of helpful v non-helpful approaches</i>	197

•	Appendices	248
•	<i>Appendix 1: Abbreviations</i>	248
•	<i>Appendix 2: Ethics Approval</i>	249
•	<i>Appendix 3: Copy of Online Survey</i>	250
•	<i>Appendix 4: Letter to interviewees</i>	266
•	<i>Appendix 5: Breakdown of nodes</i>	267
•	<i>Appendix 6: Prompts for interviewer</i>	271
•	<i>Appendix 7: Consent form</i>	272
•	<i>Appendix 8: Information for participants</i>	274

Chapter 1: Introduction

Our pleasures, joys, laughter and jests arise from no other source than the brain; and so do our pains, grief, anxieties and tears. Through it . . . we also discern ugly and beautiful, bad and good, pleasant and unpleasant. Hippocrates (Jones, 1923)

More than 26 centuries after Hippocrates wrote *De Morbo Sacro*, asserting that the brain was the seat of an individual's ability to move, to think and to feel, the human brain remains mysterious. Advances in understanding abound. Neurosurgical interventions continue to be updated in response to this understanding (Schramm, 2016, Giacino et al., 2014) as does the quality and efficacy of nursing and other interventions for those who require them (Adam and Osborne, 2016, Golisz, 2015). However, the understanding of the brain's role in our sense of self, particularly when that brain is injured, has not kept pace with such changes:

Sometime in the twenty-first century, science will confront one of its last great mysteries: the nature of the self. That lump of flesh in your cranial vault not only generates an "objective" account of the outside world but also directly experiences an internal world – a rich mental life of sensations, meanings and feeling. Most mysteriously, your brain also turns its view back on itself to generate your sense of self-awareness. (Ramachandran, 2011)

Damage to the brain changes this objective and subjective experience but does so in a way that is neither static nor straightforward to understand (Lövdén et al., 2013, Thomas et al., 2014). Functional changes to activity or performance, that which is observed or experienced, can manifest as a consequence of a range of differing, complex and interrelated issues. Understanding what it is that underpins these changes to activity, identifying the drivers behind (usually) negative changes to behaviour and ability, is what informs the response to such changes (Clark-Wilson et al., 2014).

1.1: My background and interest:

My initial contact with people with an acquired brain injury (ABI) was undertaken for neither professional nor academic reasons, “care work” was a job that I was able to obtain without prior experience or specific qualifications. I therefore commenced my career of working with people with an ABI entirely by accident. In 1991 I was employed as a local authority support worker; my role was to facilitate activities of daily living for four adults with disabilities. My employers had no knowledge of the impact of ABI and we were considered to be present solely to support the functional activities that physical impairment precluded. We received no training, supervision, documentation or monitoring. ABI was never mentioned; the only emphasis was on the physical.

I realised that the physical difficulties experienced were the least of the issues preventing our clients from leading independent lives. I had not yet developed the language to describe what I saw, but I knew that my clients were forgetful, repetitive, quick to anger and violence, ungrateful, self-centred, and seemingly could not become more “independent” of staff when we walked away from them - as they asked us to do, regularly and aggressively. They did not seem to understand their own difficulties. I now understand that neither did we, the team that were paid to help. The charity Headway informed us of the local presence of the UK’s first community brain injury rehabilitation outreach team. This organisation later worked with us to change our behaviour, and from this came positive changes for the clients, who, I now learned, were in fact brain-injured.

That experience sparked a lifetime’s interest, leading to this thesis. It was apparent to me at this early point in my career, and later during my social work training when ABI was not mentioned once, that knowledge of the condition was severely lacking. As such I was aware that there was little evidence upon which to base social work assessments and interventions. More than twenty years after I qualified, a search in 2016 of the leading UK social work journal, *The British Journal of Social Work*, identified only four articles that contain the phrase ‘acquired brain injury’ (Matka et al., 2010, Collings, 2008, Redley et al., 2010) only one of these relates directly to working with the client group (Holloway and Fyson, 2016).

I have witnessed first hand the negative outcomes associated with practice based upon a lack of understanding of the condition and have experienced the benefits to injured people and their families when the reverse is true.

In the case of very profound injury to the brain, this is complicated far further by changes in treatment, diagnosis, neuro-imaging and pharmacology. This has lead to some of those previously defined as in a persistent vegetative state in fact being more accurately assessed as conscious, to some degree, of their environment and possibly able to benefit from rehabilitation efforts and/or be able to communicate (Fins, 2015b, Fins et al., 2007). With such changes to understanding come significant ethical questions, including issues of the “right to die” (Fins, 2006). Landmark research has identified stark challenges to that which was previously believed:

We used functional magnetic resonance imaging to demonstrate preserved conscious awareness in a patient fulfilling the criteria for a diagnosis of vegetative state. When asked to imagine playing tennis or moving around her home, the patient activated predicted cortical areas in a manner indistinguishable from that of healthy volunteers. (Owen et al., 2006)

A misdiagnosis of a persistent vegetative state (PVS) can lead to decision-making regarding treatment, including the removal of life-sustaining interventions (Fins, 2012), yet evidence indicates that up to 40% of such diagnoses are incorrect (van Erp et al., 2015). Further evidence in the literature identifies that which was thought impossible, good recovery from PVS, in one case seven years post diagnosis (De Tanti et al., 2016, Sancisi et al., 2009, Avesani et al., 2006).

Such developments in diagnosis, in treatment and in understanding have taken place during my working lifetime; that which I would have held as the “truth” is nothing of the sort. Similarly, during the course of my career, developments in our understanding of the impact of injury and how to provide effective rehabilitation and support to those who do regain consciousness have also taken place (Stuss et al., 2008, Giles, 2001). Where researched, this is overwhelmingly situated outside of the social work literature

however. My profession is not keeping up with these changes despite the impact that this has upon individuals and society (Mantell et al., 2012).

1.2: Prevalence of Acquired Brain Injury in the UK

Data collected in the UK suggests that, on average, 445 people are admitted to hospital with a head injury every day (Headway, 2015b). Road traffic accidents, assaults, falls and sporting injuries can cause traumatic injuries to the brain; diseases such as encephalitis and meningitis similarly cause damage, as do incidents of anoxia, haemorrhage and the idiopathic consequences of neurosurgery for tumour or cyst removal, aneurysm clipping or invasive treatment for severe infection.

566 people per 100,000 of the population were admitted to UK hospitals in 2013-2014 for reasons of ABI and admissions are noted to have increased by 10% since 2005-2006 (Headway, 2015b). Survival rates for people with ABI have increased as a consequence of improvements to paramedicine, neurosurgery, neuro-imaging and intensive care treatment; the development of artificial ventilating systems has had a direct impact upon mortality rates (Powell, 1997, Fins, 2015a, Klemen and Grmec, 2006). Despite these improvements ABI is still noted to be the commonest cause of death or disability in those aged 1 – 40 years. The vast majority (95%) of admissions to hospital present with a normal or relatively unaltered state of consciousness. 0.2% of admissions will result in death during the acute phase of admission (NICE, 2014).

Whilst the majority of people reporting to UK hospitals with what is defined as a mild ABI will make a good recovery (Wilson et al., 1998), it is estimated that between 10 and 15% do not, with long-standing symptoms that affect a range of issues including balance, cognition, fatigue, executive impairment and mood and affective disorders (Iverson, 2005, Marshall et al., 2015, McMillan et al., 2012). Those who suffer more severe injuries are noted to experience a high incidence of sometimes very severe sequelae that affect all aspects of life. Difficulties with behavioural management, with cognition, executive skills, mood, emotion and physical and sensory impairments impact upon an individual's ability to live independently in the community, with their ability to work and with their interpersonal relationships (Tate et al., 1989, Fleminger

and Ponsford, 2005, Dikmen et al., 2009, Anderson et al., 2011). These difficulties regularly occur in the absence of any obvious physical impairment (Department of Health, 1996). Their impact can therefore be exacerbated by this “invisibility” and compounded by the brain-injured person’s lack of insight. Frequently the individual, their family and the wider community lack knowledge and understanding of why changes to affect and functional abilities occur following injury (Ownsworth et al., 2000, Stuss, 1991, Holloway, 2014a).

Despite evidence of the effectiveness of rehabilitation for people with ABI (Turner-Stokes, 2008, Oddy and Da Silva Ramos, 2013), a lack of adequate provision is regularly reported (Clark-Wilson and Holloway, 2015, Mantell, 2010, Gridley, 2013). The National Institute for Clinical Excellence notes that there is a lack of capacity to provide neurorehabilitation (NICE, 2014).

Research clearly points to the difficulties experienced by family, often as roles change from equals to providers of care/support and the impact of changes in personality, behaviour and community integration are faced (Anderson et al., 2012, Bishop, 2006, Nabors et al., 2002, Degeneffe, 2001, Blake, 2014). As a long-term condition this impact is felt over many years, potentially as a lifetime chronic and enduring condition, not a one-off event (Masel and DeWitt, 2010). For some, psychosocial functioning does not improve but deteriorates over time (Whitnall et al., 2006, McMillan et al., 2012, Olver et al., 1996, Fleminger, 2012). Suicide rates are noted to be significantly higher than in the non-brain-injured population (Simpson and Tate, 2007, Fleminger et al., 2003). For others the brain injury is the start of a prolonged (potentially lifelong) period of severely disordered consciousness, a state that challenges our understanding of what it means to be alive (Kitzinger and Kitzinger, 2014a, 2015).

Such varied, potentially severe and most usually life altering changes may occur to an individual but the roles that individual plays are also affected, their place within family, work and wider society (Wilson et al., 2015, Wilson et al., 2014)

ABI is therefore an area where one may expect social work to play a part, in line with an international definition of the profession as a “practice based and academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people” (International Federation of Social Workers, 2014).

UK based social workers therefore, as well as having statutory duties to safeguard, are bound by culture and professional expectation to use, create and apply knowledge in situations and settings where such application meets aims of empowerment and facilitates change when challenges are encountered by individuals, communities and families. As is discussed in chapter 2, the evidence base that informs the practice of UK social workers in relation to ABI is scant (Mantell et al., 2012) albeit the potential for contact between the two groups is significant and not uncommon (Holloway, 2014a).

1.3: Aims

I wished to investigate the lived experience of family members of persons with ABI, seeking common themes and to identify how this experience is affected by access to/use of services in particular. For the purposes of this study I did not pre-define what a “family member” was in order to not limit potential responses or exclude those non-married partners, siblings, half-siblings etc. A breakdown of family member by type is provided in chapter 4. Initially it had been intended to include friends as well as family, as reflected in the application for ethical approval, however in reality very few friends replied, those that did frequently had relationships that post-dated the injury and none were chosen to be interviewed.

By investigating in depth the relative’s experience and integrating this with what is known about ABI and about effective rehabilitation and support services, it is my aim to synthesise this knowledge and develop a greater understanding of *why* the relative’s experience is as it is and seek better ways of working that are formed by this understanding.

As is identified in the existing literature, in my practice and in personal accounts, the nature of the experience of ABI is one that can be deeply distressing and individuals lack clarity and understanding of the impact and of what will help better support them (Vogler et al., 2014). Creating knowledge that better supports an understanding of this experience may therefore reduce distress and generate greater clarity.

1.4: Objectives

In order to meet the aims I set the following objectives:

- To map published research knowledge concerning the personal and societal impact of acquired brain injury and the impact upon family members. This was done through a scoping review of the literature.
- To investigate and report on the experiences of family members of people directly affected by acquired brain injury. This was done via a survey and semi-structured interviews.
- To identify underlying processes and structures that contributed to shape experience, by integrating the findings from this mixed methods research with the knowledge-base found in the literature. This was approached through a process of critical realist abductive analysis.

These objectives were set in order to contribute to a greater understanding of the particular and distinct challenges faced by relatives of people with an ABI and to further an understanding of the relative's experience of service-provision.

1.5: Research Questions

I wished to investigate the lived experience of the family member of a person with ABI, seeking common themes and identifying how this experience is affected by access to/use of services in particular. My practice experience indicates that family members have a reduced quality of life and are often dissatisfied with the services they receive following injury to their relative. Carer strain and reduced quality of life is noted within the literature (Vogler et al., 2014), and family dissatisfaction with services identified within personal accounts of post-injury life (Maxwell, 2009). My aim in this research was to better inform practitioners working with family members, to support their

understanding of the experience of the relative and therefore inform their work accordingly, linking research and practice (Ferguson, 2003).

Owing to my own professional background and experience I have a particular interest in the impact of executive impairment, 'difficult to manage' behaviour and loss of insight have on post-injury functioning and service use. Such a presentation, I note, has a significant impact upon family and hence my interest in this research topic.

My main questions were:

- What is the experience of family members when a relative suffers an acquired brain injury?
- What is the experience of family members of the services they encounter as a consequence of their relative's acquired brain injury?
- How can social work/professional practice best be informed by the experience and knowledge of family members?

I addressed the following sub-questions in the course of exploring the answers to these primary research questions:

- What actions/input do family members have in relation to supporting their brain-injured relative?
- What services are encountered by family members and what are their views of these services?
- What do family members believe is required to support them and their brain-injured relatives better?
- What are the views of family members regarding the input provided by social workers and brain injury case managers in particular?

1.6: Structure of the thesis

Chapter Two provides a description of searches for relevant literature on the impact of ABI upon individuals, their families and wider society and for the academic basis that

social work has for engaging in this field. The results of the literature search identify the functional, behavioural and emotional impact upon individuals and their families, linking this to research into the effectiveness of rehabilitation.

Chapter 3 outlines the methodological basis for approaching the research in this manner, underpinning the decision-making process that lead to this form of endeavour to be one that best answers the research questions, aiming to reflect the relative's experience and form the basis of knowledge required for practitioners in the field. A description of the method of enquiry, ethical issues and dimensions of how the data created was analysed is included.

Chapter 4 reports upon the results from an online survey, presenting the quantitative and qualitative data that developed from this using both statistical analysis and reflecting upon the comments and results generated.

The process of analysing the in-depth interviews that were undertaken creates the themes outlined in Chapter 5. Direct quotes from relatives enables the themes to be established and their verisimilitude and credibility created.

Chapter 6 is the discussion of the knowledge that the research creates. Here I have linked the results of this research, themes and the knowledge generated by them, to the literature, identifying how the relatives' experience can be understood and used more effectively by practitioners in the field. Chapter 7 forms the conclusion.

In the course of this thesis I will argue that effective support and/or service provision is predicated upon an approach that recognises the centrality of the relative's role and understands the essential nature of incorporating this knowledge and experience. An in-depth exploration of the complexity of ABI and of its functional impact is described and themes are formed by the understanding relatives have of this experience. Linking this to the literature allows me to argue that, far from being a distraction from the business of rehabilitation and care for the injured party, the involved relative is central to the creation of a new, potentially cogent and valuable post-injury life for the

affected and their loved ones. But that it is only by understanding the relative's experience and using this to shape the response and approach given can services hope to maximise their impact and act to reduce not increase harm felt.

Chapter 2: Literature Review

This literature review is structured in 3 stages. While there are clear points of overlap, each section focuses on a specific question.

The search was undertaken as a scoping review in recognition of the benefits such an approach has when aiming to locate, analyse and summarise what is known on a particular topic (McKinstry et al, 2014). A scoping review has advantages when aiming to map the key concepts in a particular area rapidly, at least by comparison to a full systematic review (May et al 2001), for which I had neither the available resources nor, given the need to map a broad and disparate set of studies on the topic, was I working to a sufficiently specific and focused research question – an essential requirement for successful systematic review (Petticrew & Roberts, 2005). I chose a scoping study as a method of literature review owing to the absence of studies focusing specifically on family experience of ABI over the longer term and the exploratory and broader nature of the question chosen, that of ascertaining the lived experience of relatives.

A scoping review does not seek to search for specific study designs and, unlike a systematic review, does not seek to assess the quality of studies, potentially a simultaneous criticism and benefit of the approach.

A key strength of the scoping study is that it can provide a rigorous and transparent method for mapping areas of research. In a relatively short space of time (compared with full systematic review), reviewers are in a position to illustrate the field of interest in terms of the volume, nature and characteristics of the primary research. This analysis in turn makes it possible to identify the gaps in the evidence base, as well as summarizing and disseminating research findings (Arksey, & O'Malley, 2005 p. 30).

Following the identification of a research question(s) and the search for relevant literature, a scoping study selects the studies germane to the question(s), collates,

summarises and reports the results. Unlike an evidence mapping approach a scoping review should add a narrative integration of the relevant evidence (Dijkers 2015).

I initially undertook a search to identify academic work undertaken specifically by or for social workers in relation to the process of assessment of adults with an acquired brain injury/provision of services. Secondly I undertook a literature search to identify broadly what the issues and functional difficulties are for people with ABI. Lastly I searched for literature relating to the family experience of ABI.

2.1: Search Methods

I did not set date limits for the search, but found that most literature is published approximately post-1974. I had initially planned to limit my inclusion criteria to adult ABI research that was UK and social work based. However, this plan rapidly disintegrated owing to an absence of published literature, particularly for searches one and three. I therefore broadened the inclusion criteria and I was able to identify a greater body of work with relevance to social work and for family experience without being written specifically for or by the profession. My literature search eventually therefore necessarily crossed disciplinary and geographical boundaries, and drew heavily on the neuropsychological literature. Though this body of work was informative, retaining a focus on my research question within this broader field required additional exclusion criteria. I excluded:

- Studies that related solely to the neuropsychometric assessment of people with an ABI. These are specific measures and assessment tools used by psychologists and not social workers. The numbers of said articles is vast and expanding and they do not describe the experience of ABI.
- Studies related to neuropsychological processes used in rehabilitation and the promotion of adaptation to life post-injury.
- Studies written to inform medical staff about the treatment of people in the acute phase post-injury. These articles are specific to medical treating staff and not for social workers to utilise over the longer term.

- Some studies regarding paediatric injury when the emphasis of such papers was focussed on non-accidental injury and the process of child development/parental responsibility for raising children, brain-injured or not.
- Studies relating to solely to vocational rehabilitation, as vocational rehabilitation is more the sphere of Occupational Psychology and Occupational Therapy.
- Studies relating to ABI prevention.

I searched in SCOPUS, Social Care Online, ASSIA, Web of Knowledge, PsychArticles and PsychInfo using combinations of the following terms.

Search 1 Terms:

Social Work, Brain Injury, Head Injury, Executive Impairment, Loss of Insight, Assessing Capacity, Mental Capacity and Brain Injury or Head Injury, Social Work Values and Insight, Care Management and Case Management.

Search 2 Terms:

Acquired Brain Injury, Head Injury, Long Term Outcome, Outcome, Rehabilitation, Social Work, Executive Impairment, Loss of Insight, Cognitive Impairment, Neuropsychology, Neurobehavioural and Neurofunctional.

Search 3 Terms:

Acquired Brain Injury, Family, Parent, Spouse, Partner and Social Work.

2.2: Search 1 Literature relating to social work and ABI

As a social work-trained brain injury case manager I have an underlying belief that the values of the profession are commensurate with providing a suitable response to the needs of people who are brain-injured and their families and that the skills, experience and practice of social workers, in partnership with clients, families and other professions, are potentially ideal in supporting the rehabilitation and adaptation to change that brain injury brings. Social work is intended as an emancipatory and person

centred method of providing support and intervention for individuals in need (Thompson, 2002). The Social Work Task Force identifies negative outcomes associated with “poverty, bereavement, addiction, isolation, mental distress, disability, neglect, abuse or other circumstances” and the role the profession can play in ameliorating this (Social Work Task Force, 2009). Albeit others have noted that the profession is ill-equipped to undertake these roles, increasingly so (Carey, 2015) and requires greater application of a reformed ontological base to be truly holistic and effective (Bell, 2012).

Experience from my practice over twenty-five years identifies that the potential benefits of high quality social work appear significantly untapped and that, consequently, risks to people with ABI and to the wider community are unnecessarily increased. These risks can be very directly felt in terms of Safeguarding, but also less directly felt with regards to social exclusion, poorer quality of life, increased morbidity and mortality and unfulfilled human potential. I wanted to commence my literature search within my particular field of practice and professional background to identify how research informs and underpins assessments and interventions.

The questions guiding this part of the literature review were:

- *What does the literature tell us concerning the role of the social worker when working with people with ABI, in particular regarding the underpinning knowledge base drawn upon to formulate assessments and intervention decisions? What is known in the social work and other literature regarding the particular nature of ABI upon assessments of need and provision of services/support?*

To answer these questions I carried out:

1. A critical review of UK social work literature with reference specifically to the needs of brain injury survivors.
2. Following a brief review of the literature on the nature and assessment of executive impairment and loss of insight, with reference in particular to social

work, it was immediately clear that there was very little literature, written by social workers, concerning brain injury, in particular by UK-based authors. I had intended to exclude articles by social workers that were not UK-based, owing to the specific nature of the role, training and duties of a UK Social Worker. Owing to this absence of UK-based literature I drew upon other English language sources, most notably the American and Australasian body of research for this component of the review. References and information gained were however still mainly within neuropsychology and specialised speech and language therapy literature, not social work. The review questions were therefore not easily answerable without expanding the search outside the social work literature. This iteratively led to the development of the second search and a number of articles found at this point formed the basis of the second search.

3. A critical review of the interdisciplinary literature in relation to the long-term impact of ABI, identifying (non-medical) difficulties encountered by survivors to identify where such people may benefit from or be drawn to the attention of social workers/care services in the UK.

In terms of my doctoral research, this stage of the literature search was a natural starting point to identify what is already known and “understood” as the current episteme, a way of analysing the past to better understand the future (Webster and Watson, 2002). I aimed therefore to identify via a literature search *how* UK Social Workers make assessments in relation to ABI, the underpinning principles, knowledge possessed and guidance given, and to triangulate this with what is known about ABI and executive impairment/loss of insight, the needs of such individuals and where social workers may come into contact with people with an ABI and their families during the course of their working lives.

Initial Results: Search 1

With the exception of “Head Injury or Brain Injury and Insight” within PsychArticles and Psycinfo, scant useful results were found. One early finding was a structured review of the international literature concerning brain injury and social work (so far broader than

my search), carried out following followed Social Care Institute for Excellence guidelines. This aimed to identify literature, published in English, by Social Workers. It found:

Seventy-three items published between 1974 and 2009 met the search criteria, of which seven were experimental studies, 33 observational studies, 21 expert opinion works, six literature reviews and six addressing health policy/service provision. The majority of the works were from Australia (29), the United States (23) and the United Kingdom (10) (Mantell et al., 2012).

This finding confirmed concerns that the body of evidence available, undertaken by UK social workers, was very limited so it was necessary to undertake further research to broaden the possible capturing of information for this thesis. This was carried out by:

- “Snowballing” from references gained to seek further information/references.
- Expanding the search to identify key or relevant texts from outside of the field of social work, most particularly to include work by neuropsychologists and neuro-speech and language therapists.
- Consulting with experts in the field (the senior High Court Judge who manages the Court of Protection, Senior Judge Lush; the UK Official Solicitor; researchers linked to the National Institute for Health Research School for Social Care Research (NIHRSSCR); 9 UK-based, 4 US-based, and 1 New Zealand-based leading figures in the field of brain injury) to identify additional references and work in progress or recently published.
- Searching UK theses using the British Library EThOS search engine.
- Manually searching key journals: *Archives of Physical Medicine and Rehabilitation*, *Brain Injury*, *British Journal of Social Work*, *Journal of Head Trauma Rehabilitation*, *Journal of Social Care and Neurodisability*, *Brain Impairment*, *Disability and Rehabilitation*, *Journal of Social Work in Disability and Rehabilitation*, *Neuropsychological Rehabilitation*, *NeuroRehabilitation*, and *Social Work in Healthcare*.
- Searching Court of Protection newsletters and Nexus legal research engine.

Researchers from the NIHRSSCR informed me that they had experienced similar difficulties in identifying suitable research in their chosen area, seeking evidence about what works for people with complex needs (Gridley, 2013). Whilst their research was far more broadly focussed than ABI alone, only 86 papers from their originally identified 5,098 fulfilled their criteria.

Social Work and Brain Injury, The academic evidence

As a social work trained professional in the field of brain injury, it is impossible not to see the dominance of Neuropsychology as a discipline. Whilst not exclusively the case, much of the research undertaken by Neuropsychologists is positivist in nature, seeking “scientific” explanations and tests upon which to base claims to knowledge. Evans et al note that such research has an ontological assumption that there is an external reality that is measurable (Evans et al., 2010). In practice that which is measured is more likely done so quantitatively, with a greater emphasis on neuropsychometric testing rather than functional outcome (Manchester et al., 2004).

The reality of UK social work practice today is that resources are extremely limited and, as such, decisions have to be made regarding their allocation. I was interested to see if I could identify, with specific reference to ABI and UK social work, how these decisions were informed by research and whether they were based upon knowledge and any empirical evidence, bearing in mind their potential for harm or good (Chalmers, 2005). I recognise however that quantitative evidence, often perceived as inherently more likely to be “high quality”, may be given a more privileged position (Pawson, 2006) despite recognition by many that such a judgement may be flawed (Greenhalgh et al., 2016, Greenhalgh et al., 2014) as it neglects the importance of experience and that which is less straightforward to measure. Research potentially preferred (by funders), such as randomised control trials, may in fact be very hard (or even unethical) to apply to this group in practice (Turner-Stokes, 2008). There is sufficient evidence, developed across the parts of the world that have such services, that there is no realistic alternative to specialist neurorehabilitation for severely affected people in particular. Such individuals will require specialised care and hence there is no placebo, delayed

intervention or non-intervention group that can act as a straightforward control group (Prvu Bettger and Stineman, 2007). An absence of such care can lead to painful and very functionally disabling conditions, such as contracture, that are avoidable if treated properly and in a timely fashion (Zafonte et al., 2004).

Survival from ABI has increased significantly over the last 40 years (Powell, 1997, Hutchinson et al., 2016). Brain injury survivors are left to cope with consequences of their injuries: sometimes visible physical impairments but also with the invisible and complex interplay of cognitive, executive, behavioural and emotional consequences, which often occur in the absence of physical impairment (Powell, 1997, Department of Health, 1996). Prevalence of ABI survivors, both in the community and institutional settings, has increased due to the increased rates of survival. Despite these facts, the literature that underpins professional social work practice was found to be lacking. The needs of brain-injured people and their families were described in the broader literature of other disciplines and these chimed with experience from the field but there appeared a disconnect between this and academic social work.

Articles found included a number of “primers”, literature aimed at introducing ABI to a previously uninformed or poorly informed audience (Baker et al., 2002, Dean, 2006, Higham and Phelps, 1998, Lees, 1988, Stewart, 2011). Other articles highlighted the centrality of the family experience and the needs of carers (Anderson, 2006, Tyerman and Booth, 2001, Romano, 1974), difficulties accessing services (Foster et al., 2002, Wurr, 2012), promotion of independent living/different living arrangements (Brzuzy and Speziale, 1997), and reviews of (non-UK) social work service provision were recorded (Albert et al., 2002).

I found no UK-based social work literature aimed at social workers which addressed the assessment of people with ABI who experience difficulties with executive impairment and loss of insight. Yet ABI’s consequences are of significant potential importance to UK social workers in their role as state-funded functionaries. This role is commonly understood in terms of the state’s response to (adult) physical or sensory

impairment and the panoply of legislation and guidance provided, such as the Care Act (2014), National Assistance Act (1948), Chronically Sick and Disabled Persons Act (1970) and the National Health Service and Community Care Act (1990 and 2006). UK social workers therefore undertake assessments of need, make decisions regarding safeguarding and mental capacity, and act as gatekeepers to resources, without underpinning research knowledge. This has been subject to criticism, with specific reference to the consequences of this lack of knowledge (House of Lords, 2014, Summerfield, 2011, Acquired Brain Injury and Mental Capacity Act Interest Group, 2014, Holloway, 2014a, Holloway and Fyson, 2016).

My findings of an absence of research relating to ABI and social work confirm my practice experience, and are backed up by other researchers who have noted an absence of evidence (Mantell et al., 2012, Gridley, 2013). While Mantell et al specifically looked for publications related to brain injury written by social workers, Gridley et al looked more broadly than this with regards what they describe as “people with complex needs”. Whilst Gridley et al did find relevant examples of good practice, including an integrated brain injury social work service and brain injury case management, they also described finding a dearth of evidence generally.

The result of the broader literature search described the profoundly complex and heterogeneous impact of injury upon individuals, their families and communities, the epidemiology of this, and outlined the similarly varied responses, assessment options, rehabilitation and support considered efficacious that had been developed internationally and across both time and discipline. It did not identify sufficient literature to support describing or researching the social worker’s role within this process nor the relative’s experience of ABI in relation to social work and of allied services. The results from the expanded search provided a broader range of research and knowledge but this was necessarily situated outside of social work and formed the basis of the second literature search.

2.3: Literature Search 2

- *What difficulties do people with an ABI experience, both immediately post-discharge from an acute setting and over the longer term, which cause an impact for their relatives and lead to a need for support, potential service provision and/or social work input?*

The Impact of Acquired Brain Injury:

In order to consider the relatives' experience of ABI it was necessary for me to understand the impact of such injuries on the affected individual as this provides the context in which the relatives' experience emerges. Unlike the first search, which returned so few results as to require broadening, the results of this search identified a wealth of literature from outside of the field of social work. In order to structure these results, and to provide the context to focus them upon the impact on relatives, this section has been broken down into four sub-headings. These are:

Impact of Acquired Brain Injury on the individual

Impact of Acquired Brain Injury: Loss of Insight

Impact of Acquired Brain Injury: Loss of self, enforced identity change

Impact of Acquired Brain Injury: Functional outcomes for the injured party

Impact of Acquired Brain Injury on the individual

Some of the more common complaints post-ABI are: fatigue; headache; reduced processing speed; difficulties sustaining, dividing and directing attention; memory difficulties (often due to attentional deficits); "executive" functions such as reduced idea generation, difficulties planning and organising, reduced problem solving capability, reduced ability to initiate planned activity, etc.; and with what may be described as "neuro-behavioural" difficulties such as irritability, disinhibition, impulsivity, loss of empathy, egocentricity, blunted emotional responses, emotional lability, aggression and perseveration (Powell, 1997, Oddy et al., 1985, Wood and Williams, 2007). Physical or sensory impairment is an outcome of ABI for some, alongside cognitive, executive and behavioural issues (Thornhill et al., 2000). A lack of

purposeful independent activity is reported and may be associated with psycho-social and behavioural factors (Whitnall et al., 2006, Lee et al., 2016).

Whilst “executive functions” is an umbrella term for a range of concepts there is some agreement on what they include:

The Executive functions may be defined as the control or self-regulatory functions that organize and direct all cognitive activity, emotional response and overt behaviour

(Gioia et al., 2008 p. 179 - 180)

Such functions are complex to assess and therefore to respond to, as they are complex to even conceptualise (Barkley, 2012). Experience from practice would indicate that these are the factors that complicate assessment, intervention and our understanding of what may facilitate rehabilitation and support. For individuals to not recognise or understand their own abilities or difficulties with executive functioning is therefore predictable, it is complicated to do so. There is evidence, in the non-brain-injured population, that people are generally poor at predicting their own ability to exercise executive control (Nęcka et al., 2012). When compared to loss of limb or spinal cord injury, brain injury has the potential to be more complex in both the assessment of need and the formulation of interventions, owing to the range of domains that may have been affected by the injury and the interrelationships between them. Quality of life post-ABI would appear correlated with return to a healthy and productive lifestyle, valued by the individual (Corrigan et al., 2001). As post-traumatic growth and recovery is possible (Hawley and Joseph, 2008, Powell et al., 2007), knowing what is more likely to support and promote such positive change is required.

Executive impairments are difficult to assess in formal settings, a situation exacerbated by poor insight as such assessments depend, in part, upon self-report of abilities and are frequently ex-situ (Struchen et al., 2008). Executive impairment is best assessed over time, in real-life settings and with evidence from third parties. There is no straightforward table-top testing that accurately replicates executive impairment in

real-life functional settings and such tests are considered to have low ecological validity (Manchester et al., 2004, Barkley, 2012). This is recognised in the English and Welsh Courts where the argument that an absence of clear impairment on neuropsychometric testing equated to the individual concerned having no executive impairment was rejected. In this case judgement on the matter was important in establishing that test results alone do not have primacy over observed functional difficulties (*Verlander v Rahman*, 2012). Sir Robert Nelson adjudged in this case that triangulation of evidence, above and beyond testing, was required and primacy did not rest with tests alone.

The failings of neuropsychological testing alone as a method for assessing executive impairment were identified within what many would describe as the seminal work in this field (Lezak, 1976). They are also noted in much earlier work, though the language used today to describe executive impairment is absent (BMJ, 1945). Work continues in the field of neuropsychology to develop tests that are considered to have more ecological validity (Knight et al., 2002, Burgess et al., 2006, Jansari et al., 2014).

To provide one example from practice of the difficulties associated with executive impairment and its assessment, I would note that difficulties with problem solving can have, as their root, difficulties with idea generation. When this is the case, problem-solving strategies cannot simply be applied by the brain-injured party, as the options to weigh up and decide between them cannot be generated in the first place. In this instance a difficulty with idea generation can become a significant handicap to an individual, particularly when dealing with novel situations. This has an impact upon functional independence and employability. Experience shows that difficulties with idea generation and initiation are often misattributed to issues of motivation (notwithstanding the fact that poor idea generation and the associated task failure experienced may be demotivating per se). A lack of insight into this difficulty may compound the problems faced by the injured party as all “blame” for failure and difficulty is externalised and so learning opportunities are limited. A neuro-behavioural response, experienced by some, simply to reject ideas provided by others (organic egocentricity) is further disabling for those who cannot idea generate (McMillan and

Wood, 2017, Wood and Williams, 2007). How such difficulties are understood and assessed is key to planning and implementing services required to meet need and prevent social exclusion.

As difficulties with executive functioning in performance are affected by interacting variables that shift over time, including cognition, emotion and fatigue, then variability of performance is to be expected (Stuss et al., 2003). Decision making and reasoning are also noted to have an emotional component (Brown, 2011) and affective disorders are common post-brain injury (Deb and Burns, 2007, Ashman et al., 2006). The perceived threat to self-identity that ABI may bring has been observed to affect ability to engage with rehabilitation and support services, requiring careful management (Ashworth et al., 2011). It is difficult to gauge therefore how to take account of this complexity and variability in a one-off assessment meeting. Such an approach however underpins and affects the formulation of a social worker's plan for intervention as care management approaches take precedence (Dustin, 2006, 2007).

The outcome for individuals who experience such injuries is, understandably, very variable (and varies temporally for an individual) and this variation is in part dependent upon site and severity of injury but also on pre-morbid, co-morbid and environmental factors (Ponsford, 2013). Extensive research has been undertaken to identify what are the main drivers behind outcome from ABI. Injury related measures and factors such as neuroimaging findings, lowest Glasgow Coma Scale (GCS) rating, duration of Post-Traumatic Amnesia (PTA), presence of other injuries, cognitive and behavioural impairments, demographic factors (including age, gender, genetic status, education, pre-injury IQ and employment status), and social factors including family and other social support, are all found to be implicated in outcome (Ponsford, 2013). In this sense the condition is one that may be considered to be "bio-psycho-social," where outcome is intricately linked to a range of interlinked biological, psychological and social factors. Though earlier uses are identified in the literature (Ghaemi, 2009), credit for popularizing this model is usually accorded to Engel (1977), whose primary concern was to humanize medicine through a greater appreciation of equal relevance of psychological and social dimensions of illness. In the context of brain injury, attempts

to isolate neurological damage from the context in which it occurs negates the reality of life post-ABI and are described as reductionist and flawed (Engel, 1980). A bio-psycho-social approach, one that does not seek to pathologise or separate the injured party from the dynamics of their condition, their personal situation, their environment and their society is recognised as providing a more holistic and realistic base from which to provide rehabilitative and support services (Williams and Evans 2003, Yeates et al 2008b, Ounsworth et al 2006). Such an approach integrates developing knowledge of neural development/neuroplasticity with recognition of the personal, cultural and social factors that influence decision making, functioning and opportunities (Zittel et al 2002, Garland and Howard 2009). Whilst some caution of the risks of the potential for dominance of the medicalising “bio” aspects of the approach, a balanced, critical engagement and understanding of this dimension is noted to potentially strengthen holistic and ethical practice (Healy 2015). Certainly, it is hard to see how professional practice that is inadequately informed by an appreciation of the neurological, alongside the psychological and social, can effectively benefit individuals and their families (Holloway, 2014a).

Impact of Acquired Brain Injury: Loss of Insight

A further complexity, not unique to ABI, is that loss of insight into the condition by the injured party is common. Whilst complete loss of insight into physical impairment (anosognosia) is relatively rare, poor self-awareness of cognitive and, in particular, executive impairment is not (Prigatano, 2005). To a degree this is logical and understandable as the injured party is more likely to have had pre-accident knowledge and understanding of what physical impairment is and feedback gained from failure to be able to carry out a physical task, such as standing, is very direct and even painful. It is possibly worth noting at this juncture that 90% of people with an ABI are noted to make a good physical recovery (Higham and Phelps, 1998). Opportunities to learn and therefore adapt to direct changes in physical function are more explicit and easily understood (Hart et al., 2009).

One’s capacity to develop self-awareness of cognitive or executive difficulties is, experience shows, more difficult. Opportunities to learn from feedback are less direct,

require greater levels of abstract reasoning to process, and the capacity to apply this learning across time and settings is impaired. Abstract reasoning itself is an executive function that may be impaired by brain injury. The skills and abilities required to develop and maintain insight are precisely the ones affected by the injury. Physical impairment can therefore predominate to the exclusion of factors that may prove more disabling, most especially when insight is affected. Mantell describes this straightforwardly thus:

Where there are clear physical disabilities, these can easily become the focus of attention, neglecting the impact of the damage to the brain. Often the person may have no physical impairment, but lack insight into their needs. Consequently, they do not look like they need any help and do not think that they need any help, so not surprisingly they often do not get any help
(Mantell, 2010).

Loss of insight/reduced self-awareness following ABI is the subject of intense investigation, most usually by neuropsychologists. Poor self-awareness following brain injury is common, particularly in the earlier stages of recovery (Prigatano, 2005). This is often in the context of no discernible loss of IQ as well as no visible impairment, making the process of assessment and understanding an iterative one of enquiry and not simply a prescriptive or reactive one. Assessment solely focused upon the person with an ABI's view of their needs will therefore be intrinsically flawed. This is in conflict with the fact that notions of "personalisation" are privileged despite being conceptually undermined, sometimes to the point of being valueless (Holloway and Fyson, 2016).

Difficulties with poor insight/reduced self-awareness are associated with poorer rehabilitation outcomes (O'Callaghan et al., 2012), increased carer burden (Ergh et al., 2002) and increased levels of carer distress (Prigatano et al., 2005), and is a risk factor for behavioural disturbance (Bach and David, 2006). In practice, difficulties with insight are associated with difficulties engaging the client with rehabilitation, support and vocational activities (Medley and Powell, 2010).

To help conceptualise loss of insight in these circumstances, Crosson generated a hierarchical pyramidal model to describe three levels of awareness post-ABI. These levels are Intellectual, Emergent and Anticipatory awareness, with Anticipatory being the highest level of awareness (Crosson et al., 1989). In this model, people with 'Intellectual' awareness of their difficulties are able to state what their problems are, e.g. "Since my accident my memory is terrible," but are unable to put in place any strategies to compensate for this. They do not recognise when they are experiencing a failure as a consequence of their memory difficulties and are not able to adjust their behaviour accordingly. This knowledge is therefore solely "intellectual" in nature. This is a highly confounding factor for assessment, as the brain-injured party would appear fully cognisant about their difficulties, wholly aware of their impairment. In practice, as this knowledge is purely intellectual, it does not affect the behaviour of the injured party and therefore does not affect their functioning and/or functional independence. Any assessment that takes place in the absence of corroborating evidence and/or observation (relying purely on self-report) may therefore very easily miss the needs of the brain-injured party (Prigatano, 1996).

An individual who has developed *anticipatory* awareness, the highest level in this model, will recognise their post-ABI impairments, be able to state them and be able to act, consistently, in accordance with this knowledge. Such an individual would be able to predict, for example, that undertaking too much in one day would challenge their ABI-related fatigue and therefore pre-plan not to do so. Such individuals consistently and effectively adjust their behaviour, pre-emptively, using compensatory strategies and aids, to avoid difficulties in real-life functioning. Individuals who experience *emergent* awareness are able, in common with those with an intellectual awareness, to state their post-ABI related difficulties. In real-time and real-life settings, individuals with emergent awareness will experience task failure, as they have not consistently pre-planned to take account of their difficulties, but they are able to note when this is occurring and so may be able to change their behaviour/expectations of themselves in the moment as a consequence of environmental feedback.

To further confound assessment and understanding, individuals with an ABI may demonstrate different levels of awareness in different domains of impairment. Most usually have a higher level of awareness for physical difficulties than for executive ones (Prigatano, 2005).

The remediation of poor self-awareness can be a rehabilitation goal (where possible), supporting individuals to develop insight in to their condition and what will support them to “rehabilitate” and/or “adapt” (Fleming et al., 2006). Such an approach is recognised to support both the injured party and their family/carers (Medley and Powell, 2010, Holloway, 2012). Improved self-awareness is also associated with increased likelihood of independent living (Malec and Moessner, 2000).

Notwithstanding this complexity, the impairments and difficulties caused (as a consequence of ABI) have a functional impact upon activities of daily living, engagement and social integration, employment and use of services. As such, people with an ABI can experience a diminished quality of life (Horneman et al., 2005) with significant levels of social exclusion (Oddy et al., 2012a). These are the very areas of life that UK social workers are able to address. Therefore whilst social workers may not be *aware* of ABI, there are numerous arenas, described later, where they will be in *contact* with people with an ABI.

Impact of Acquired Brain Injury: Loss of self, enforced identity change

“The loss of self is often the real tragedy of traumatic brain injury.... it is a loss so profound that many never recover from it. Brain injury strips away a lifetime of learning, of personal identity, and personal power. The loss is a soul shattering experience, intense and intimate. It is so intimate that society as a whole averts its eyes and closes its ears to the pain and despair of such a naked soul. It is a soul bedeviled by infantile demons, the very stuff from which neurosis and psychosis is made.” (Brain Injury Resource Center, 2016)

Experience of working with individuals with life altering consequences of brain injury leads to troubling questions of the meaning of self-identity. Injured people sometimes disassociate themselves from their behaviour (e.g. “this is not me”) and express the view that the “real” them is the pre-injury one. The post-injury manifestation is seen as an unwelcome imposter, who is not liked or even accepted as real. That such discrepancies lead to affective disorders is perhaps wholly unsurprising (Cantor et al., 2005, Schwarzbald et al., 2008), with suicide being a feature of the condition in the chronic phase (Simpson and Tate, 2007).

Earlier work in the field focused on the organic nature of the injury to the changed personality (Eysenck, 1967). This unidimensional description has been challenged by bio-psycho-social approaches to brain injury that recognise a complex interplay of factors leading to loss of self-identity (Thomas et al., 2014, Ylvisaker and Feeney, 2000). The more nuanced models of this particular type of loss lead to notions of possible treatment and support to reconstruct a coherent sense of self (Ylvisaker et al., 2008, Yeates et al., 2008b).

Poorer quality of life is regularly reported along with loss of structures such as work and friendships that sustain and develop identity over a lifetime (Juengst et al., 2015, Jacobsson et al., 2010, Williamson et al., 2013). Sometimes subtle changes to social communication ability affect the capacity to make and/or sustain friendships (Shorland and Douglas, 2010) and obtain or retain employment (Meulenbroek et al., 2016), with loss of the self-definition, status, and financial and social benefits that employment brings.

The nature of this loss of identity and the threat it presents are described as “voids” within a self-narrative (Nochi, 1997). Nochi described three separate if interconnected areas where the self was lost following injury. He identified losses created by pre- and post-injury comparisons made by the injured party; these were augmented by the sense individuals had of being labelled by others as a consequence of the injury (Nochi, 1998b). A lack of clarity about how to proceed, how to change things, sustains this loss of self and forms the final “void”.

As our understanding of ABI as a lifelong process develops (Masel and DeWitt, 2010) so does the suggestion that the adjustment to the condition is also continuous and cyclical. Contained within this is the creation and ongoing development of new identity (Muenchberger et al., 2008). For many of those who leave inpatient settings and return to the community, this adjustment and change to a new self most likely takes place outside of formal supportive settings. It is “real world” feedback that highlights the discrepancies between pre and post injury and this is where support is recognised as being required, both in terms of rehabilitative input but also support to adjust to the new-self, as this is central to the process (Haslam et al., 2008, Dewar and Gracey, 2007).

Such a complex process, adjustment to such radical change, is set within the context of the cognitive and executive impairments experienced, potentially overarched by difficulties with insight. This is perhaps a uniquely cruel aspect of brain injury; the abilities required to develop a new self-identity (and cope emotionally with the meaning of this) are the same abilities that the injury can damage (Prigatano, 2005). This mirrors the intrinsic difficulty with the development of insight where the skills required are the ones impaired. Development of self-awareness, often a goal of brain injury rehabilitation, is noted to increase levels of depression as individuals grow to learn the meaning of what has occurred to them and the impact it has upon their present and their future (Fleming et al., 2006, Fleminger et al., 2003), their past being an unobtainable and dislocated place. Post-injury psychosis is rare but does occur (Schwarzbold et al., 2008, Simpson et al., 2011). Perhaps it is here that the that “soul shattering” experience of “pain and despair” is felt (Brain Injury Resource Center, 2016)?

Yet, despite the significance and severity of the situation people with an ABI may find themselves in, stories of post-traumatic growth and of learning in and through adversity form part of the literature too (Evans, 2011, Von Mensenkampff et al., 2015, Gelech and Desjardins, 2011). A unidimensional approach, one that focuses solely on loss of such overwhelming magnitude, runs the risk of invalidating the reconstructed

lives of the many individuals and families who face ABI. Failure to recognise adaptation, progress and the value of hope negates the day-by-day struggles faced by many and runs contrary to notions of meaningful healing (Mattingly, 2010, Flesaker and Larsen, 2012). There are occasions in practice when it appears that hope is the only resource a brain-injured person or their family members have left. Working with (not against) this hope is identified in literature as useful as it has intrinsic value (Bovens, 1999), can be used intentionally as a therapeutic tool (Hollis et al., 2007) and lead to shared hope between practitioner and patient/client and family member (Moore, 2005).

People with ABI (and their relatives) contribute highly personal accounts of their travails (and triumphs) and social media increasingly provides opportunities for blogging and peer support (Bauser, 2003, Crimmins, 2001, Massey, 2016). Such narratives by people with an ABI, written or verbal, are noted to be a part of recovery and rehabilitation, a method of reconstructing 'new-self' on a journey towards stability or even post-traumatic growth (Easton, 2012, Fraas, 2015, Nochi, 2000). The facilitation of narrative, the support provided to people with an ABI to reconstruct life both via rehabilitation but also by promoting a new narrative to describe self, is integral to the practitioner's endeavour (Butera-Prinzi et al., 2014, Segal, 2010); these are 'neuro-narratives', autobiographical accounts by those affected directly or indirectly by neurological injury or disease. (Todd and Weatherhead, 2013, Easton and Atkin, 2011). Such work has been identified outside the field of ABI as a method of incorporating an understanding of interventions and how they benefit from being sited within the patient/client perspective (Weiner et al., 2013) where a more holistic (bio-psycho-social) approach to work is beneficial to outcome (Hurwitz et al., 2008).

Promotion of post-traumatic growth, the concept of having "gained" something from a traumatic and life-changing event, goes beyond notions of rehabilitation and restitution (Tedeschi and Calhoun, 2008). Complete recovery following a severe brain injury is unlikely, with long-term outcome described as poor for those who are defined as disabled one-year post-injury (McMillan et al., 2012), and psycho-social deterioration over time is noted as an outcome for some (Whitnall et al., 2006). Practice to support post-traumatic growth is therefore potentially work that can

navigate through and past the wished for, but unlikely to be achieved, desire for full restoration. Calhoun and Tedeschi have pioneered this work, applying it to various client groups and types of trauma experienced (Calhoun and Tedeschi, 2006b), and refining it over time to identify the role of “expert companion” as essential to the task (Calhoun and Tedeschi, 2012). For this to occur notions of rehabilitation must be broadened to incorporate an understanding of a sense of ‘new-self’ and of the reconstruction of a valued and coherent identity that has meaning for the individual and family concerned. This is therefore post-trauma “growth” of sorts, rather than a backwards-looking attempt at a total reconstruction that serves only to continually identify loss by its inevitable lack of completion.

Impact of ABI: Functional outcomes for the injured party

Because outcomes are so varied and unpredictable, and because of the many challenges to effective understanding and intervention that I have explored in this chapter, individuals are often left inadequately supported (Headway, 2015a). Unsurprisingly, considering the broad impact ABI has upon functional abilities and behaviour, affected individuals can come to the attention of non-specialist services. This in turn is part of the experience of the relatives of people with ABI.

Research into prevalence of ABI rates in UK male prisoner populations shows concerning levels of injury (Williams et al., 2010) at around 60% and a meta-analysis of previous studies indicating a prevalence rate of 52% (Shiroma et al., 2012). Preliminary findings from the largest UK study undertaken to date, on behalf of the Disabilities Trust Foundation, indicated that of prisoners with an ABI, 73% reported that the brain injury predated their first offence, 71% had experienced more than one traumatic brain injury (and 30% had experienced 5 or more traumatic brain injuries), 43% had been in prison 5 or more times and 80% had a history of drug use. Prisoners with an ABI were 3 times more likely than non-brain-injured prisoners to have held only partly skilled or unskilled jobs or to have never been employed (Pitman et al., 2012). Similarly, probation officers are noted to lack knowledge of ABI and, in particular, to underestimate difficulties relating to lack of insight, relying heavily and mistakenly upon self-report by prisoners (O’Rourke et al., 2017).

ABI amongst homeless populations has been assessed at around 48% with 90% reporting acquiring a brain injury prior to becoming homeless (Oddy et al., 2012a). Whilst this research cannot identify ABI as having directly caused an individual's status as a homeless person, a failure by social support agencies to integrate such knowledge into plans for re-housing them runs the risk of establishing future loss of accommodation. The skills required to maintain a tenancy are challenged by cognitive and executive impairment and by difficulties self-managing behaviour.

Return to work, post-ABI, is complex and an early study (Brooks et al., 1987) demonstrated that employment rates dropped from 86% to 29% post-severe injury and that "the presence of cognitive, behavioural, and personality changes was significantly related to a failure to return to work." (p.5). More recent work identified a 40% return to work rate however the cohort studied included those with what were defined as moderate brain injuries (Friedland and Potts, 2014). Research into employers' attitudes towards applicants with a declared ABI rated similarly to those applicants who declared a history of schizophrenia (Bricout and Bentley, 2000).

Prevalence of ABI within UK psychiatric settings/users of psychiatric services appears not to have been interrogated. Within the limited US studies available, prevalence of traumatic brain injury in psychiatric settings notes increased rates of injury compared to controls, increased severity of injury compared to control groups and increased likelihood of the presence of more than a single incident of brain injury (Burg et al., 1996, McGuire et al., 1998). A large US study ($n=1,440$) by Fann et al identified that the relationship between ABI and psychiatric conditions can and does operate in both directions with those defined as having a psychiatric illness as being 1.6 times more likely to have a subsequent ABI than those without (Fann et al., 2002). With specific reference to schizophrenia and traumatic brain injury Molloy et al undertook a meta-analysis of research available and found that there was an increased risk of developing or of being diagnosed with schizophrenia post-traumatic brain injury of 60% (Molloy et al., 2011).

As rates of ABI amongst UK-based psychiatric service users do not appear to have ever been established it is not possible to state how many people are misdiagnosed/misplaced as having mental health problems with no reference made to their brain injury. Experience from practice would suggest that this is not unusual, particularly in the case of brain injury in childhood/adolescence leading to an altered development by the young person concerned (Fleminger, 2008). Professionals in mental health settings would be expected to come across people with an ABI but who may not self-identify as such, and therefore their assessments and interventions will not be informed by the underlying nature of the presenting condition.

Once the initial acute phase of the condition has passed, the injury itself had not previously been noted to foreshorten life expectancy except where unmanaged post-traumatic epilepsy or profound physical impairment develop. Life expectancy therefore had previously thought not to have been affected or at least not greatly affected (Conroy and Kraus, 1987). McMillan's work in Glasgow however, a 13-year prospective study, would appear to raise very significant doubts about the commonly held view that death rates, post-acute phase, are similar to those of non-brain-injured people. This found an increased likelihood of mortality, assessed as 2.8 times community controls (McMillan et al., 2011). Cause of death was not noted to be directly related to the brain injury itself.

This significantly increased rate of mortality raises questions regarding why this should be the case when the explanation is not simply medical in nature. It would not appear to be the brain injury per se that is causing death but the impact of the brain injury upon day-to-day functioning. It is recognised that this cohort of injured people are potentially experiencing cognitive and executive difficulties and, as per the Thornhill cohort, may well be living without any formal or even informal support in the community (Thornhill et al., 2000). It may be questioned whether an absence of support or rehabilitation to compensate for cognitive, executive, behavioural and emotional difficulties foreshortens life? Possible examples of how this might occur include lack of ability to manage a balanced diet and/or recognise medical need and comply with medical treatment.

More recent work by McMillan on mortality following mild traumatic brain injury over a 15 year period post-injury identified that younger adults (aged 15–54 years) who had suffered a mild brain injury had a 4.2-fold greater risk of death than matched community controls. This was a prospective case-controlled population study with an n= 2,428 brain-injured adults (McMillan et al., 2014). Similarly in the United States, a large retrospective study identified significant deterioration in functioning many years post-injury for some and makes the argument that ABI is a chronic condition that requires an understanding of this chronicity to form a suitable response (Corrigan and Hammond, 2013).

Work by Corrigan et al into prevalence of traumatic brain injury amongst service users at a dual diagnosis (substance use and severe mental illness) US treatment centre identified that 72% of their cohort were brain-injured. Perhaps more importantly, it was noted that the participants with a brain injury had commenced drug use at a younger age, had worse functioning and had a more severe diagnosis of mental ill health. (Corrigan and Deutschle, 2008) Further work by Corrigan notes that childhood ABI is associated with more complex substance use disorders (Corrigan et al., 2012).

Research from a large birth cohort in New Zealand (McKinlay A, 2002) has identified that rates of problematic drug and alcohol use in early adulthood for those who suffered just a mild brain injury aged between 0 and 5 are three times that of their non-brain-injured peers and they are also five times more likely to be arrested for crimes of violence. The significant impact of even mild injury in childhood has been identified to impair a wide range of health and social outcomes (Sariaslan et al., 2016). It would seem apparent therefore that ABI is implicated in increased likelihood of an individual coming into contact with a variety of health and social care agencies, even if the underlying condition is neither recognised nor understood.

Each of these functional outcomes described impacts upon family members.

2.4: Literature Search 3

- *What is known in the literature regarding how family members experience, are affected by and are involved with the consequences of ABI upon their relative?*

Impact of acquired brain injury: The Family

Whilst the make up and functioning of families will vary considerably, culturally and within a single family across time, the notion of a sense of interdependence between family members (as well as independence from each other) is often held (Covey, 2014). ABI will therefore affect more than the individual concerned, also impacting upon family/social group. As a heterogeneous condition affecting families that are likewise very diverse, the nature of the impact varies enormously.

Research into the impact of ABI upon family members has identified significant levels of stress and burden upon relatives (Perlesz et al., 1999). Cognitive, emotional and behavioural changes in the person with ABI are noted to be the strongest predictor of clinically significant anxiety and depression for family members and of unhealthy family functioning (Ponsford et al., 2003).

Children of people with an ABI are noted to be negatively affected, with 48% of children in one study found to suffer symptoms of PTSD (Kieffer-Kristensen et al., 2011), and are at high risk of emotional and behavioural difficulties (Butera-Prinzi and Perlesz, 2004, Uysal et al., 1998). The behaviour of brain-injured parents has been implicated in significant harm to children (Summerfield, 2011). Skilled and specialised social work and brain injury case management intervention has been identified as a method of supporting parents with an ABI to support their children (Holloway, 2016, Holloway and Tyrrell, 2016).

Relationship breakdown has been noted to be high in some studies (Wood and Yurdakul, 1997). However, in surviving relationships, significant alterations in role, identity, security and loss of previously held future options and beliefs change the relationship greatly (Godwin et al., 2014). Sexual health and behaviour is noted to be

negatively affected for many (Simpson and Baguley, 2012, Simpson et al., 2013). Loss of friendships is noted to be common (Rowlands, 2000, Prigatano and Gupta, 2006) affected by issues as varied as facial recognition ability (Knox and Douglas, 2009), loss of conversational abilities (Shorland and Douglas, 2010) and alexithymia (Williams and Wood, 2013). Literature focussed upon supporting relationships post-injury is frequently based around notions of improving communication and communicational abilities (Togher et al., 2016, Togher, 2013, Murphy et al., 2015), improving functional outcome by changing the approach undertaken by the non-injured party in particular.

The literature relating to paediatric ABI contained work with an emphasis on identifying and supporting behavioural change by parents to support the engagement with and management of children with an ABI as well as with the impact felt by said parents. Interventions to improve parenting abilities are identified (Brown et al., 2015, Brown et al., 2014), some focused on parent coping style (Prihadi et al., 2015) and others upon supporting return to education (Andersson et al., 2016). The direct impact upon parents was identified as being significant (De Kloet et al., 2015, Heary et al., 2004).

Fewer studies were found that focused upon the relationship between adults with an ABI and their parents (Kao and Stuifbergen, 2004, Knox et al., 2016, Jones and Morris, 2013, Wongvatunyu and Porter, 2008a, Wongvatunyu and Porter, 2008b). Those that did usually focussed upon the change in relationship between the adults and difficulties with perceived independence and longer-term concerns. The impact upon siblings, including adult siblings with or without a formal care role, is less well investigated still (Degeneffe, 2016, 2015, Degeneffe and Olney, 2010).

The impact upon family/carers is identified as being a risk for development of psychiatric and other health difficulties (Moules and Chandler, 1999). The burden experienced is greater than that for carers of people with other conditions (Jackson et al., 2009) and carers report having needs unmet by adequate service provision (Blake, 2014). Carer burden is noted to increase over time and not to plateau or improve (Levor and Jansen, 2000, Jordan and Linden, 2013).

The nature of the trauma experienced by family is one where the security provided by the assumptive world can be lost, and previously held beliefs about and for the future are shattered (Kauffman, 2002). Unlike bereavement, the nature of this loss is ambiguous with the injured party physically present, alive, often saved by skilled medical intervention, and yet altered: a personality potentially so changed as to be unrecognisable in some instances, more subtly changed in others. The nature of the very condition itself sometimes prevents the injured party from understanding or accepting that they have changed, potentially having lost the capacity to empathise or pay attention to the needs of others too.

Ambiguity in this context is defined as a lack of clarity.

When the adjective ambiguous is used to describe a loss, it means there is no validation or clarification of the loss, and thus a lack of knowing whether the lost person is irretrievably lost or coming back again (Boss, 2006, p.144).

Such ambiguous loss is identified as unresolved grief (Boss, 1999a), where popular notions of “closure” and acceptance are made impossible by the nature of the loss itself (Boss and Carnes, 2012). Put most simply, there is no body to bury, and no culturally accepted ceremonies to support the “non-bereaved” as there are with death. Life goes on but grief remains “frozen” (Boss, 1999b) as the ambiguity and the loss experienced combine to create an obstacle to coping and grieving (Boss, 2006). Family members are noted to lack a “road-map” (Jordan and Linden, 2013). The experience is described as:

... a lifelong journey of understanding disabilities and impairment while working to accept the changes that have occurred in one's life. Caregivers embark on a parallel journey of coming to terms with a “new normal” as the person they once knew is forever changed due to the brain injury (Petersen and Sanders, 2015, p. 1).

Boss and others note that this ambiguity experienced by family members produces ambivalence, a sense of conflicted (potentially entirely contradictory) emotions and feelings (Boss, 2010). These feelings of ambivalence can be so severe as for parents of brain-injured people to both love and wish their children dead at the same time (Webb, 1998). Such ambivalence, when set in the context of invisibility of impairment and a brain-injured relative that lacks insight into their condition - who can neither empathise nor be grateful for the support they receive - places family members under extreme stress (Ergh et al., 2002). Lack of support from the wider community and attitude towards people with an ABI can compound these difficulties (Linden and Boylan, 2010) whereas increased resilience of family members is noted to correlate with positive outcomes in relation to family well-being (Simpson and Jones, 2013).

Impact of ABI: The role of the family in support, care and rehabilitation

As noted, the impact of ABI upon individuals is varied, can be extreme, can prevent return to pre-accident functioning and create changes in relationships. The impact upon the non-injured family, as also noted, can be devastating with relatives thrust into a position for which they have little prior knowledge or understanding and one which has a significant impact upon them and their well-being too. Professionals tasked with providing specialist neurorehabilitation and support are therefore working within a changed family system, most usually where long-term outcomes will not be clear at commencement.

Research indicates that involving family members in rehabilitation has a positive impact upon the outcome (for the family member) (Moriarty et al., 2015) and that poorer family functioning has a negative impact upon outcome for the person with the ABI (Sander et al., 2002). There is some evidence of the benefit of involving family in behavioural management programmes, the impact being beneficial to behavioural management but not to reduction in carer burden (Fisher et al., 2015).

Research, predominantly in relation to dementia and psychosis, identifies that the relative's coping style and expressed emotion has an impact upon recovery or well-being of the affected individual (Butzlaff and Hooley, 1998, Scazufca and Kuipers,

1998). Caution needs to be shown in extrapolating these results to the situation regarding ABI, however such issues are noted in practice too. The outcome for the affected person is worse when the relative is critical of behaviour. With ABI such a coping style is noted to be harmful for the relative's health (Blake, 2014, Breitborde et al., 2009) and for the functioning and well-being of the injured party (Alway et al., 2012), but can be positively changed by specialist service provision (Fortune et al., 2016).

2.5: Literature review conclusion

ABI is noted therefore to have a significant impact for individuals, their families and the wider community. Decision-making and resultant action/inaction by the injured party can bring such individuals into contact with (often costly) services, but not necessarily specialist ABI ones or even non-specialist ones but with an awareness of the condition.

Evidence exists in the literature of the impact of ABI in terms of increased rates of mortality (not directly related to the injury itself), reduced academic achievement/participation in education, increased rates of relationship breakdown, loss of informal support networks, very significant carer burden, increased (and serious) risks to children, reduced participation in work (with the concomitant reduced income and loss of self-identity this creates), poorer mental health and suicidality and increased rates of homelessness and incarceration, often within the context of problematic alcohol and drug use and of significant recidivism.

The nature of the injury, particularly those aspects relating to executive impairment and emotional and behavioural difficulties, takes time to manifest. These aspects are not readily apparent for simple assessment and the person with an ABI is not always aware of them. There are therefore implications for the long-term nature of need for (and style of) service provided to such people to promote recovery and rehabilitation but, just as importantly, to prevent deterioration.

ABI is therefore common. That the brain-injured party themselves may not self-identify as brain-injured is a complicating factor. The impact of the injury, as noted above, is social exclusion from which the injured party is severely restricted from addressing themselves without external input as an inherent consequence of the injury itself; this is axiomatic.

The literature describes a complex panoply of difficulties at a functional, behavioural, emotional and psychosocial level. This has an impact above and beyond simply the affected individual alone. My research interest is to relate this literature to the lived experience of the relative, to ascertain how on a day-to-day and year-by-year basis this experience and the involvement (or not) of services serves to affect the involved but uninjured family member. Understanding what underlies changes in functional ability and behaviour supports relatives (and professionals) to understand better why an injured person acts (or does not act) in a certain way (for their own benefit) and how difficulties can be ameliorated in future. This supports greater understanding of what structures and strategies can be best employed to limit the functional impact of the injury. The social work literature in particular does not currently provide either the underpinning knowledge of ABI to help define this, nor a method for responding to it. It is not helpful for either the family, the injured person or the professional.

Chapter 3: Methodology and Methods

3.1: Methodological Position

Experience of working with brain-injured people leads me to observe that, whilst the condition may only be directly experienced by one person in a family, the sometimes devastating impact of the injury is sharply felt by other family members (Booth, 2006). It is a family condition and relatives who have insight and understanding of the changes encountered are considered by some to be more emotionally affected than the person with the ABI (Headway, 2015c).

Effective support and rehabilitation for the consequences of ABI therefore inherently has to incorporate family. Not to do so is to fail to address the reality of the injury and its outcome and is a function of the individualising approach sometimes taken by clinicians (Newnes, 2006). Researchers similarly are noted to have an individualist approach, impacting upon the topics investigated and serving to limit the literature relating to family (Yeates, 2007).

In terms of epistemology, I am increasingly comfortable with taking a critical realist approach to help understand and develop knowledge to affect practice (Evans et al., 2010). This philosophy, developed initially by Roy Bhaskar, is concerned with ontology, the study of being. Bhaskar argued that it is not possible to reduce statements about the world (ontology) to statements about our knowledge of the world (epistemology); this was what he described as the epistemic fallacy of positivism (Bhaskar, 1975). Bhaskar also argued against an unstructured view, rejecting a solely interpretivist philosophy that suggests multiple realities. For Bhaskar social structure is a necessary condition but human agency is necessary for social structure to change.

For critical realists therefore there is a single reality, but there are multiple interpretations of it; social construction forms a part of this interpretation but is not its entirety. It is an approach that is not based solely upon predictions or hypotheses that

can be tested to establish truth or falsehood but is instead a method of creating explanations by uncovering and understanding causal mechanisms, in particular for subjects and areas of research that are not easily suited to more reductionist empirical and quantitative testing.

For social science research the context is part of the causal explanation not an irrelevant factor (Pawson and Tilley, 1997). Both positivist approaches of logic/numeric data and interpretivist ones that claim there is no independent reality are too simplistic for complex problems that require an integration of approach. Critical realism is a framework for melding these opposing paradigms together. In doing so independent reality is accepted but cannot be researched without inherent bias, or without taking context into account.

By applying a critical realist approach an understanding of the perspectives and meanings made by research subjects is developed, recognising these as real phenomena and central to the endeavour. Critical realist approaches help to explain phenomena, emphasising the importance of context in influencing how mechanisms lead to outcomes. Single events, case studies and multiple narratives and understandings can be used rather than reliance upon general laws that have to fit every case (Maxwell, 2004).

ABI may be seen to commence as belonging to the sphere of medicine, moving towards neuropsychology once acute life threatening conditions have stabilised and medium to longer term impact is felt. However ABI is *experienced* by individuals and families. It is a social condition, or perhaps more accurately a bio-psycho-social one (Ownsworth et al., 2006, Williams and Evans, 2003). Such a non-reductionist understanding of the condition of ABI fits well with a critical realism's need to recognise the importance of context and failings of a purely positivist approach.

I start from the ontological assumption that ABI is a fact, that it has an impact upon the lives of those it affects (Powell, 1997), that the impact can be lifelong (Masel and DeWitt, 2010), and that there are services and support that can be given to reduce this impact and assist rehabilitation and adaptation (Clark-Wilson et al., 2014). I make the assumption that the way a service is delivered, the style of that service and level of service received has an impact on the effectiveness of the input (Turner-Stokes, 2008). I make the assumption that the specific knowledge and experience of a worldwide community of individuals, practitioners and researchers has informed the iterative development of specialist (if fallible) neurorehabilitation and support services (Malec, 2009, Prigatano, 2005, Jackson and Manchester, 2001).

Whilst not exclusively the case, much of the research undertaken by neuropsychologists is predominantly positivist in nature, seeking “scientific” explanations and tests upon which to base claims to knowledge. Evans et al. (2010) note that such research has, as a significant ontological assumption, that there is an external reality that is measurable. By taking a critical realist perspective it is possible to incorporate the context in which phenomena are experienced and understood to help explain the underlying causal mechanisms.

3.2: The dominance of positivism in the “neuro”-world

Neuropsychometric tests may well support our understanding of whether someone with a brain injury is recovering/rehabilitating (in the sense that their test scores change over time) or may facilitate comparison between individuals, but they have limited capacity to predict outcome and actual functioning (Manchester et al., 2004, Ponsford, 2013, Verlander v Rahman, 2012) and are subject to interpretation in their design, their use and in the analysis of the results found. Validity and reliability of such tests are questioned and caution with interpretation is required (Franzen, 2000). The increasing and worldwide body of quantitatively derived empirical research into ABI has facilitated a greater degree of understanding of the range of possible outcomes and needs an injured person may have, but such tests are only ever indicative, not

prescriptive or exact (Patry and Mateer, 2006). Patterns in outcome and of impairments can be identified but are relatively broad-brush. Large-scale research may, for example, support our knowledge of likely mortality and factors that are predictive for mortality post-severe brain injury but do not provide an exact guide as to who will live and who will die (Utomo et al., 2009). The body of epidemiological evidence relating to brain injury, positivist in design, shapes and forms my assumptions relating to the the outcomes of brain injury (Corrigan et al., 2010, Corrigan et al., 2014). Increased rates of unemployment, incarceration and suicide may be statistically identifiable and defined and these statistics subject to to regular reinforcement by repeated research, meta-analysis or systematic review (Saltychev et al., 2013, Shiroma et al., 2012, Bahraini et al., 2013) but such research does not set out to describe the experience, does not seek the affected party's knowledge and their interpretation of events. Context is either neglected or intentionally excluded despite the importance it may have upon forming results or reporting how phenomena are experienced. Rates of unemployment and other key indicators measured are themselves constructs, varying temporally and across borders, subject to judgement and classification that form that construction.

The quantitatively based work I use to form my assumptions is therefore neither as clear cut as may be presupposed nor does it directly provide complete answers for what can be done to support positive change. Correlations may point us towards interventions that have a perceived evidence base but the strength of that evidence is created by the method used to find the correlation and the assumptions and constructs that underpin it. There is a risk of epistemic fallacies developing if the means of arriving at conclusions or beliefs are flawed. To take a perhaps frivolous example, over time the divorce rate in Maine is very closely correlated with the US per capita consumption of margarine, but there is no currently understood causative link however and, logic would suggest, unlikely to be one (Moosa, 2016). This demonstrates how overly simplistic application of statistical correlations in the absence of context and an understanding of how those correlations were developed may not therefore provide the evidence desired to substantiate claims. Whilst I find

myself relying upon more positivist research to underpin my broad understanding of ABI, I reject the notion that there is an easily and directly measurable external reality that can identify how brain injury is experienced. The context in which it occurs affects outcome, as it is a social, psychological as well as a medical process (Richardson et al., 2014). Similarly I would reject the notion that ABI is only a social construct (Burr, 2015) whilst wholly accepting that social constructs, such as societal response to injury and disability, are mediating factors in how such injuries are experienced.

Whilst I am surrounded by positivist thinking from neuropsychologist colleagues in particular, I value the co-construction of new narratives in my daily dealings with brain-injured families. Much of my work is an endeavour to facilitate their struggles to assert a re-shaped identity, enabling people to define and understand themselves anew in a world that rarely sees or comprehends the challenges of their situation (Muenchberger et al., 2008). Most usually ABI is a lifetime condition for which there is no cure, self-identity has been disturbed, and the previously understood “narrative” of the individuals and family unit concerned disrupted significantly and permanently but changeably and opaquely. Rehabilitation, support, adaptation and acceptance may assist an individual and family to maximise their recovery but change, particularly for those who are severely injured, is inevitable and invariably unwelcome, initially at least (Whitnall et al., 2006). Therefore practitioners working with brain-injured people and their families must recognise that it is this “reconstruction of self” via understanding of meaning and felt experience that mediates positive change (Gracey et al., 2008, Martin et al., 2014, Segal, 2010). If brain-injured people and their families experience a loss of former identity and this loss creates a “void” that can impact upon ability to make progress (Nochi, 1997, 1998a) then supporting the creation of “new-narrative”, enabling new and valued meaning to be generated is part of the professional endeavour (Dewar and Gracey, 2007, Ownsworth, 2014). If this loss of identity is viewed as a consequence of the bio-psycho-social, not simply as a “fact” of injury rooted in neurology alone, then a more effective response would embrace all of these factors, including family perspectives (Yeates et al., 2008b). The act of story telling, facilitated perhaps by the professional, thereby enables new identities to be created

and recovery to be promoted (Fraas, 2015, Easton and Atkin, 2011, Easton, 2016). Rehabilitation and other interventions must be reframed from the simply mechanistic to the holistic, taking into account the need for a life to be lived not simply performed. Such an approach promotes more cogent social sense-making in contexts where dissonant views may be held by family members (Yeates et al., 2007).

I am also aware that positivist cognitive and executive tests and definitions are not precise binaries but are constructs in and of themselves, albeit often useful ones in an indicative but not a prescriptive way (Manchester et al., 2004). We all live in relation to our skills, experience and abilities, and our belief systems, our mood and our social milieu can be as protective as they can be damaging. Ultimately “recovery” and quality of the life lived can only be self-defined, sometimes simply in the moment, and this is the construction of the individual’s truth (Ownsworth and Fleming, 2011, Powell et al., 2007). Quality of life measures and rating scales are used to endeavour to research general or specific populations more objectively (Ware and Sherbourne, 1992, Truelle et al., 2010) potentially showing useful trends over time or between populations. However, by their nature the measures will reduce questions of significant complexity to brief scales and so are not informed by what experience, view, value or belief has lead an individual to pick that particular numeric value when answering a question. Such information is simply not recorded.

Preceding the research undertaken for this thesis I undertook a mixed methods approach to researching quality of life following ABI. This identified that the measure used had an impact upon the results gained, reflecting an intrinsic bias. The specialist tool used to support self-assessment of quality of life post ABI depended upon some metacognitive ability and the possession of insight. False positives were therefore created by those who lacked insight, as this cohort’s quantitative results identified a higher quality of life which was contradicted by the qualitative interviews undertaken with the same injured parties and those that knew them well (Holloway, 2014b).

In practice the potential divide between more positivist colleagues and others with more constructivist tendencies manifests in a debate over the usefulness of solely quantitative outcome and goal attainment measures. This appears to be based not solely upon theoretical arguments for the primacy or otherwise of such measures but also upon the imperatives and priorities of funders, who apparently prioritise easily measurable outcomes. The *internal* validity of randomised control trials (RCTs), the apparent gold standard of medical and quantitative research, is perceived as being higher placed in the hierarchy of evidence (Concato et al., 2000, Rothwell, 2005). However the *external* validity (generalisability) of such studies is more questionable (Fuller, 2013). A systematic review of 283 RCTs in major medical journals identified that 81.3% of these studies had excluded patients for reasons of common co-morbidity. Other studies had excluded on grounds of age, gender and use of other medications. The generalisability of such RCTs is therefore questionable across populations (Van Spall et al., 2007). The use made of statistics, in particular to the exclusion of other methods, has been viewed as removing subjectivity from research, and this is considered a good thing by reducing or eliminating researcher bias, statistics being potentially less value laden and offering greater opportunity for replication or generalisability. However, the basic premises upon which this is founded are also questioned, as statistical analysis and its interpretation may also be subject to bias, even if less obviously so (Nuzzo, 2014, 2015).

Irrespective of potential for bias and questions regarding external validity of quantitative research, errors in the use of statistics and reporting inconsistencies are found (Nuijten et al, 2016). Significant statistical errors, affecting validity of conclusions, were noted in a number of quantitative works that were examined to test the accuracy of the calculations used:

Moreover, around 15% of the articles contained at least one statistical conclusion that proved, upon recalculation, to be incorrect; that is, recalculation rendered the previously significant result insignificant, or vice versa. These errors were often in line with researchers' expectations

(Bakker and Wicherts, 2011 p. 666).

Unquestioned or unnoticed such results, given credence and cited by others, may form future research despite the basic premise of their foundation being inaccurate.

Richness of experience and qualitative data are bypassed by work that solely focuses on the quantitative, despite the fact that not all experiences will be well served by RCTs (Smith and Pell, 2003). The evidence for evidence-based medicine (EBM) is questioned when the tools used to generate said evidence have the potential to be reductionist (Greenhalgh et al., 2014, Greenhalgh, 2012).

With its well-intentioned methodological fetishism and quantitative biases, EBM is well suited to producing abstracted generalisations based on population samples. EBM isn't inherently wrong, but it plays to a vision of science that is characterised by predictive certainty (Greenhalgh, 2012, p. 96)

Such an approach can lead to flawed hierarchies being developed, and also exclude qualitative research despite the impact it may have on practice and the creation of knowledge (Greenhalgh et al., 2016).

A more nuanced understanding of research processes however may reject the binary of positivist quantitative work versus interpretivist qualitative work and understand that each may inform the other. A common example cited in favour of EBM is that ground-breaking and life-saving advice for parents to place their infants on their backs when they put them to bed resulted from major trials, replicated around the world (Blair et al., 2006). This change in advice was however prompted (and the trials established) because one of the research team, Professor Fleming, spent time talking to bereaved parents listening to them describe the night their child died. It was from these conversations that an idea sprang, though his findings were initially rejected by colleagues (Perkins, 2016).

I aimed to answer my research questions by eliciting narrative from family members and to situate the analysis of this in the body of knowledge generated outside of the lived experience. Whilst recognising the value of the relatives' stories in and of

themselves (Emihovich, 1995) it was the intention of this research to provide useful support for practitioners in explaining and providing a context for the relatives' experience, looking for patterns and themes that can better inform practice. The drive behind undertaking the work in this way was informed by the argument that research has a purpose outside of itself alone and that my profession is an applied discipline, using knowledge in practice to seek solutions to problems (Martinez-Brawley, 2001).

An absence of knowledge by social workers about the very condition of ABI itself (Mantell et al., 2012, Holloway, 2014a, Holloway and Fyson, 2016) affects the response given by the profession in practice, in social work education and in the literature, privileging continued ignorance in the absence of understanding that ignorance (Dunning, 2011). The socially dominant (if ignorant of knowledge) professional is placed in a position of power that leads to the marginalisation and denigration of the Other, preventing shared learning (Kumashiro, 2000). An unquestioned and dogmatic adherence to notions of "client as expert", despite the very nature of severe ABI making this unlikely, initially at least, removes the professional's duty to act to learn and seek a realistic appraisal of the situation. A misplaced view, lacking in nuance, of the sanctity of "choice" places individuals lacking in information, lacking insight and lacking ability at risk, and simultaneously makes them responsible for this situation (Holloway and Fyson, 2016, Fyson and Cromby, 2012, Fyson and Kitson, 2007, Galpin and Hughes, 2011).

Addressing this professional illiteracy, based in lack of awareness of the condition and its impact upon individuals and families, is the motivation behind this research and it is approached by investigating the experiences of families and how they have been impacted by their experiences.

3.3 Study Design

The literature search carried out prior to undertaking fieldwork for my thesis highlighted a large gap between the needs of brain-injured families and the response provided to them by social workers in particular (Holloway and Fyson, 2016). For my fieldwork I undertook a mixed methods approach comprising an online survey of the

relatives of brain-injured people, followed by in-depth semi-structured interviews. This approach is one that developed and self-informed as it progressed and is sited in the lived experience of the family member (Goodson and Gill, 2011). I used an inductive thematic analysis approach as the first step in interpreting, understanding and reporting my findings (Guest et al., 2012, Braun and Clarke, 2006), which then informed an abductive analysis aiming to go beyond the 'surface-level data' and identify the generative mechanisms that, within specific contexts, shape the outcomes for family members.

Whilst recognising the limitations of an on-line survey approach, discussed below, I used this as a component of the research, partly to identify common themes and experiences reported by relatives, partly to inform the questions for the semi-structured interviews and partly as a tool to identify those that are willing and able to engage in the more in-depth semi-structured interviews. I undertook this overall approach as a way of seeking a broad range of lived experience from as wide a population as I was able, looking for patterns and themes and incorporating this with the richer and more detailed information gathered by the in-depth interview process. The design of the on-line survey and its distribution targeted all individuals with a relative with an ABI, not seeking to privilege specific sub-groups.

In taking this approach a tension potentially develops when looking for generalisability which is more commonly associated with quantitative research as a basis upon which it may be judged (Kerlinger and Lee, 1999). Groleau et al. (2009) argue that by using a sequential design during qualitative research and confirming (or not) that the data generated is mutually supportive, the external validity of the work increases the possibility of generalisability. Having an online survey that informs the in-depth interviews is an example of such sequencing, albeit the interviewees were chosen from the questionnaire respondents and so are not independent of them. As this study incorporates quantitative data from the online survey with the qualitative data generated by the interviews, a larger sample is created with, from this perspective, increased potential for generalisability.

Polit and Beck provide a list of possible approaches and safeguards that increase the possibility of research findings being applicable outside of the subjects of the research. They note that, amongst other things, being immersed in rich data, using mixed methods, integrating findings with other literature and seeking replication to the point of data-saturation supports this. They do also however caution about the notion of generalisability, pointing instead to positioning research within its context (Polit and Beck, 2010). This is congruent with a critical realist framework, within which the 'open-system' nature of social phenomena, and resulting significance of contexts, lead to an emphasis on 'demi-regularities' (Fletcher, 2016) and theoretical generalisability rather than direct replicability across diverse settings.

I chose a mixed methods approach owing to the nature of the issue at hand. ABI is a bio-psycho-social condition, experienced over time (by individuals, families and communities), and is one that is experienced in the context of use/non-use of health and social care services. The critical realist argument that the method chosen should best fit the issue under investigation was one that resonated with me (Olsen 2002). Using and integrating qualitative and quantitative data supports research in instances such as ABI where the condition can not be fully or satisfactorily understood through solely reductionist or interpretivist methods.

A mixed methods approach enabled the data generated from the free-text component of the online survey, the interview data and the quantitative survey data to be contextualised and triangulated with the literature to create a richer source upon which to develop conclusions. The qualitative element allowed for personal experience to be situated in the quantitative data in a way that could not have occurred if a simply qualitative or quantitative approach was undertaken.

Qualitative methods can help to illuminate complex concepts and relationships that are unlikely to be captured by predetermined response categories or standardised quantitative measures. (McEvoy and Richards, 2006 p71).

This study has endeavoured to increase the potential for identifying generative mechanisms with potentially wide applicability by including quantitative and qualitative approaches, by seeking respondents from across a large geographical area and by incorporating the rich data from interviews with the literature and the survey responses.

3.4: Online Survey

Criticisms of online surveys identify the potential for these to skew results according to the biases inherent within internet use, to favour those with access to and ability with technology and, in this instance, sufficient proficiency in English to follow the survey instructions (Evans and Mathur, 2005). Conversely it has been noted that the quality of data gathered by online surveys is higher than that of more traditional postal collection methods with fewer errors, fewer missing items, and fuller responses to open-ended questions (Barrios et al., 2011). In practice one individual did make contact with Sussex University during this phase of data collection and requested a paper copy of the survey. This was provided along with an SAE, but was not returned.

Internet use in the UK in the year the online survey took place indicated that 84% of households had access to the internet and that usage was skewed towards males and younger people although 42% of people aged 65+ used the internet on a daily basis (ONS, 2014). The potential to reach a wide audience was therefore high and the results, reported in chapter 4, identify a broad age range of respondents with a significant predominance towards females (84.5%).

One perceived advantage for this research of utilising an online survey was to facilitate the engagement of individuals from all areas of the UK, excluding Scotland. It was decided to exclude Scotland because of differences in Mental Capacity legislation, which is relevant for people with a brain injury (and therefore the experience of their relatives), and for pragmatic and cost reasons regarding travel. The online survey provided the possibility of anonymity for respondents, facilitated ease of data collection and analysis, and enabled the survey link to be provided to a wide range of

organisations and services who were well placed to distribute this to relevant individuals.

Such an approach did however exclude those who have absolutely no contact with any form of service, professional or voluntary sector, and those without sufficient proficiency in English. A further group excluded by such an approach was those individuals who suffer ABI but are not identified as having done so, and either receive no professional input or become users of non-brain injury services such as homelessness, prison or mental health services. (Holloway, 2014a, Oddy et al., 2012a, Williams et al., 2010, Corrigan et al., 2012, Boccaccini and Brodsky, 2002) Non-attribution of post-injury difficulties to the ABI by family members will exclude them from accurate identification of need and therefore from the on-line survey. Relatives of individuals who had died post-injury, potentially as a consequence of functional changes in behaviour that were not addressed or supported sufficiently, were also missed by this method (McMillan et al., 2011). Furthermore relatives of individuals who had made a good recovery from ABI and had limited contact with services would not likely participate. These factors combine to create a “non-response bias”. Whilst it is not knowable with certainty, it is possible that the respondents are not fully representative of this wider sampling frame and so a degree of sampling bias is inevitable (Sax et al., 2003). The implication of this is to reduce the potential generalisability of the study.

The online survey (appendix 3) was targeted specifically at the relatives and friends of people with an ABI. The survey provided a number of closed questions, Likert scales and five open-ended questions, allowing some space for free narrative by respondents to identify areas of difficulty not suggested to the respondents by the closed questions or Likert scales.

Respondents were asked to rate, on a scale of one to ten, the most difficult and/or regularly encountered ABI-related issues their relative experienced. I identified these difficulties from the literature, from practice and from the documentation and other

output from ABI charities. Respondents had the opportunity to note what services they had encountered related to their relative's ABI, to rate those services and were provided with the space to comment upon what "worked" and what did not. Finally the survey gave respondents the opportunity to state if they would be willing to be interviewed, face to face, to generate more in-depth information and data about their experience.

To distinguish between those who completed the survey and those who both completed the survey and were interviewed face to face, I refer to the former as *respondents* and the latter as *participants* from here onwards.

The survey was created using *Survey Monkey* and a confidential link was created for distribution.

When discussing the online survey with an eminent neuropsychologist colleague I was interested that he criticised the notion of asking family members to rate, using a Likert scale, the relative difficulties an individual may have in domains such as physical impairment, behavioural difficulties, loss of insight, etc. He voiced concerns that the relatives may "get this wrong" and that, without objective formal testing, independently undertaken, against which to measure their assessment, there would be no possibility of comparing across the sample. I believe that this would be a fair criticism if the research was focused upon issues other than the relatives' perceptions. The design and intention of the research, in line with the research questions it endeavours to address, is sited within the relatives' lived experience as they perceive it. The criticism is however entirely fair if I had endeavoured to use the ratings scales as a de facto proxy for more objective testing, following a positivist approach to achieve perceived impartiality. This assertion of the relatives being "wrong" in their assessment has an interesting mirror in work relating to brain injury rehabilitation where the importance of personal construction/reconstruction is noted as key; the converse of this serves instead to negate the highly personal "lived" nature of reformed/reforming identity (Yeates et al., 2008a, Gracey et al., 2008). For this study, it is the relatives' experience and view, and the generative mechanisms that contribute

to shaping it, that is central. Attempts at perceived objectivity in this instance will at a minimum lose the personal construction of the experience and at worst serve to negate it.

3.5: Recruitment: Online Survey

Having worked in the field of ABI for over twenty-five years and having been an active member of various fora and groups I was able to use my contacts and connections to draw the link to the survey to the attention of the relatives of brain-injured people across the country. I individually contacted each of the 100-plus Headway* groups, Headway National, the Child Brain Injury Trust (CBIT), United Kingdom Acquired Brain Injury Forum (UKABIF), the Brain Injury Rehabilitation Trust (BIRT), the Brain Injury Social Work Group (BISWG) and the British Association of Brain Injury Case Managers (BABICM) as well as many personal/professional contacts built up over the years. Professional intermediaries therefore supported the research by drawing this to the attention of relevant individuals either directly or via their organisation's websites/Facebook groups etc. In doing so I aimed to capture a broader base for possible respondents geographically but also, of relevance to my research, including people who had limited contact with services.

**Headway: "The National Brain Injury Charity" has a central office and over 100 smaller branches that are autonomous but linked to the national organisation.*

3.6: Data Collection, online survey responses

A number of people who were relatives of people with conditions other than ABI completed the survey and the data generated by their input, whilst interesting for me, was not included in the findings. Similarly a number of people with brain injuries completed the survey despite the clear instructions regarding inclusion criteria. Again the data generated was of interest but the results of these particular surveys were also not included in the findings.

In total 110 completed surveys were accepted.

3.7: In-Depth Semi-Structured Interviews

Completed online surveys generated 48 responses (from 110 in total) where the respondent agreed that they were willing to be interviewed face to face. These individuals provided contact details, including the first half of their postcodes, and from this it was possible to achieve a very broad geographical spread of respondents. A number of individuals identified that they or their relative received no professional input or support.

Prior to launching the online survey and as part of the ethics application, a broad sense of the likely topics and areas of interest that may form the questions in the semi-structured interviews was developed and approved (ethics approval certificate appendix 2).

To guide the process to enable the research questions to be answered a “prompt sheet” of possible questions was developed (see appendix 6: Prompts for interviewer). These prompts and questions developed from previous experience and from reviewing the results of the online survey. The intention of the questions was to elicit their account of the family, the accident/injury and the development by the relative of experience and knowledge of their changed situation. This was facilitated by asking questions about life before and after injury and use of services over time. The relative’s views were sought as to “what works?”, what makes a good professional/service and asking what advice they would give others in a similar situation.

3.8: Interview sample size

The decision of how many people to interview with the intention of gaining sufficient and reliable data is subject to debate. The notion of “data saturation”, the idea that no new categories or interconnections between data are achieved after a particular number of interviews, ideally guides the decision of how many people to interview (Glaser and Strauss, 1968). It is noted that issues such as homogeneity amongst the

interviewees, the breadth of the claims that the research purports to make and the methodological approach are also factors to be considered when deciding sample size (Mason, 2010).

A lack of rigour in explaining methodological decisions regarding sample size has been criticised (Marshall et al., 2013) and reporting of the decision making behind sample size is recommended (Francis et al., 2010).

Some writers have attempted to create mathematical formulae to make explicit the reasoning behind decisions regarding numbers of interviewees (Fugard and Potts, 2015), creating a tool to support this, although others have criticised the notion this is premised upon (Byrne, 2015, Emmel, 2015, Hammersley, 2015). Smith et al recommend that interviewing 4 to 10 participants is sufficient for much research; however this is in the context of using an interpretative phenomenological method of analysis (Smith et al., 2009).

Research has identified that, when reviewed in hindsight, a high proportion of codes are established early into the interview series. A systematic analysis of a research project of reproductive health amongst 60 African women identified that 34 of the 36 codes eventually developed were present after the 6th interview was coded and 35 of the 36 by the 12th (Guest et al., 2006). Wray et al. offer a contrasting perspective, that of specifying numbers of interviews being an error made by attempting to judge qualitative work by the same standards as quantitative research. They highlight that applying a quantitative paradigm leads to a failure to recognise that added data may in fact lead to lower quality of analysis. As each life and experience is unique, “saturation” in this sense cannot exist and so, particularly with emotionally difficult subject matter, simply focusing upon higher numbers of interviews brings with it an increased risk to the researcher’s well being for little gain (Wray et al., 2007).

High-minded commitment to ensuring that the number of interviews is sufficient to reach “saturation” is however potentially undermined by the managerial governance

of research by universities where Ethics committee and academic approval for a project, if interview numbers proposed, are agreed *prior* to interviews taking place. Potentially this difficulty may be overcome by agreeing in advance a more flexible approach, with a range of interviewee numbers, rather than exact figures, being proposed. This, along with the somewhat elastic notion of what saturation actually is, leads some to be critical of its unquestioned application (Green and Thorogood, 2014, Mason, 2010).

On top of academic and managerial governance issues sits the practical one of access to possible interviewees, time for interviewing and the volume of data generated by interview, particularly for this project where an online survey also existed.

Prior to launching the online survey, during the research proposal phase, I hoped to interview sufficient individuals to ensure that the data I collected was enough to both generate and substantiate themes and provide breadth and potential contradictions and/or “outliers” (Seidman, 2013, Guest et al., 2012). Ultimately, in this study, pragmatism informed the decision regarding numbers of interviewees. It was predicted that interviews would not be brief, as the subject matter is complex and has a significant emotional element; experience of undertaking assessments of people with an ABI, with their relatives present, for clinical or medico-legal work regularly highlights this. Being a lone researcher with no colleagues upon which to rely for data collection or analysis therefore limits this study. A larger sample size of interviewees might have contributed different data and produced additional themes, while a team of experienced researcher colleagues might have brought other useful perspectives to the analysis, but this was not feasible.

3.9: Choosing the interviewees

As the number of respondents who agreed to be interviewed was greater than my capacity and need, a more purposive sampling method was required to identify interviewees.

A more detailed examination of the willing respondents identified that 16 of them were known either to me or to the organisation I work for. I excluded these individuals on ethical and methodological grounds as, because of this pre-existing relationship, there was a risk that individuals might feel obliged to take part or to seek to provide me with the answers that they perceived I wanted to hear.

I collated (on Excel) the responses of the remaining 32 possible interviewees, intentionally excluding data relating to age, geographical location, gender, time since injury, cause of injury etc., and focusing instead upon the relative's description of the profundity and type of difficulty experienced post-injury as measured by the online survey's Likert scales and free responses.

It had been my intention, as described in my research proposal, to choose to interview those family members who identified greater difficulties with executive impairment, lack of insight and post-ABI behaviour rather than those who identify that their brain-injured relative has greater difficulties with physical impairment and/or have high nursing needs. The rationale behind this was that those who look unimpaired (and may even believe themselves to be so for reasons of loss of insight) are those who are hardest to assess and provide services for (Mantell, 2010). Research into the factors that underlie and are associated with increased use of independent case management services indicates that it is loss of insight and behavioural issues that are most strongly correlated with service usage (Clark-Wilson et al., 2016). These are the issues that relatives identify as being most difficult for them (Koskinen, 1998, Carroll and Coetzer, 2011), more so than physical impairment. It is therefore the experiences of their situations that I chose to focus on, in the belief that this would provide greater insights into the generative mechanisms leading to their outcomes.

In the event, after a whole day of considering which individuals to interview, it became clearer to me that there was a number of individuals who were described as having significant impairments (without significant physical impairment) and a number who were described as having significant impairments *with* significant physical impairment. I therefore made my selection of interviewees to ensure that both groups were

represented, with severity of difficulty being the guiding principle for inclusion. When the decisions became more marginal and choices needed to be taken between very similar responses I returned to the original survey and chose based upon the volume and quality of the free narrative writing, favouring those who wrote more above those who left these sections blank or gave one word/very brief answers. “Quality” of the free narrative writing in this sense was not defined by grammatical ability or correct spelling but by the sharing of a “story”; the intention being to identify those who seemed most willing to share their experience in detail. Whilst such an approach may run the risk of privileging those with greater educational attainment, in practice the interviewees came from a variety of backgrounds.

This sampling method identified 16 potential interviewees, all of whom agreed to be interviewed when approached. I had estimated that the interviews would take between 90 and 120 minutes each. The interviews took place between October 2014 and February 2015 and were recorded on a digital device and transcribed in full. Interviews averaged 127 minutes in duration, the shortest being 68 minutes and the longest being 181 minutes.

Two interviews were cut somewhat short by the brain-injured person returning to the home. A further interview was interrupted for a period when the person with the ABI returned home prior to going out again. No data collected from the transcribed recordings during the periods when the brain-injured person was present has been analysed or used within this thesis.

3.10: Logistics

The decision to exclude from consideration for interview all potential candidates with whom I had a current or prior connection via my employment, previous employment or medico-legally had a logistical impact as the vast majority of my practice has taken place in London and the South East, the area in which I reside. This resulted in the need for considerable travel, totaling some 4,813 miles for the sixteen interviews.

The nature of the task of interviewing an individual at length and relating to a history that was potentially distressing for both interviewer and interviewee lead to a decision to interview a maximum of one person per day and not to undertake more than two interviews in any one week.

3.11: The Interviews

All 16 interviews took place as planned, 15 in the family member's home, one in a public place (as was the choice of the interviewee). One interviewee wished to be interviewed with her (non-brain-injured) partner present.

Upon arrival at one property I ascertained that I had in fact worked, very briefly, for 3 meetings only, with the family concerned some 16 years earlier when working for a previous employer. There had been no professional connection between myself or my current employing organisation and the family since this time. The interview proceeded as planned but I have had to exercise greater caution when using the data and information gathered during this interview to prevent my potential influence being included as independent comment.

The rationale behind the research was discussed with the interviewees and they were asked to "tell their story", an approach which allowed them freedom to structure their narrative and its salient points in ways which made sense to them. Prepared interview questions (see appendix 6) were asked if the interviewee did not spontaneously address them in the course of his/her own narrative. In practice, however, the interview schedule was rarely required as the interviewees spoke at great length and in detail, and often covered the ground that the questions were to focus on.

Typed transcripts of the 16 interviews totaled 614 pages (344,091 words).

3.12: Ethics

During my professional career I have encountered a large number of very resilient and able relatives of people with an ABI. However such individuals are potentially

vulnerable, particularly perhaps when being asked to recount the story of their loved one's brain injury and the losses/changes that have occurred subsequently.

Measures to reduce risk to respondents and participants included:

Protection of respondents (Inclusion Criteria):

- The survey sought responses only from those whose experience of ABI is at least two years in duration. This allowed for greater opportunities for adjustment, post-traumatic growth and robustness than would a shorter period.
- The survey was aimed only at those respondents aged 18 or over. Family members who were under 16 years of age were excluded from the interviews owing to a lack of capacity to reasonably ascertain "Gillick competence" via an online survey. Concerns around a duty of care and not being able to meet these in practice lead to a decision to aim the survey and subsequent interviews solely at over 18's. In the event no survey responses were received by individuals under the age of 18.

Protection of respondents (completion of survey)

- The survey was placed upon the websites of known support agencies. As such, respondents were aware in advance of their contribution of sources of potential support should their involvement have proved emotionally provoking for them.
- The survey details were distributed to professional contacts within the field and asked to be brought to the attention of potential respondents who they adjudged fit the relevant criteria and were robust enough to take part. These individuals were already connected to specialist support services by definition.
- The survey contained signposting for sources of support and of contact details for my doctoral supervisors at Sussex University in case concerns or difficulties were raised by respondents.
- A predictable ethical issue was that of the impact of family members feeling that they had not been acknowledged or heard within research that ostensibly set out to gather and communicate their views. Part of the rationale for the on-

line survey approach was to firstly ensure that I drew respondents from a broader base, to avoid being channelled towards those that were known by my service or equivalent and, more importantly, to ensure that no family member volunteered themselves for interview and was rejected without having had the opportunity for their story and their voice to be heard and incorporated. Space for voluntary submission of a more detailed narrative was allowed for and, as will be seen, was very well used.

- The survey specifically requested that contact details or identifying details were not included unless the respondent wished to become a participant in the in-depth interview process.

Protection of participants (interview):

- Families that had a professional or personal connection with the Head First organisation (my employer) were excluded for consideration for interview to prevent these relationships colouring the research and expectations regarding future service use.
- Family members with fewer than 2 years experience of being a relative of a person with an ABI were also excluded from the interviews. Whilst in part this served a purpose for the research, interviewing people with greater experience over time, the ethical reason for such exclusion related to participant emotional well-being. Experience shows that relatives in the earlier stages post-injury are more likely to utilise a functional but fragile denial mechanism, have hope that is unlikely to be met by experience and to have not begun to adjust to their changed circumstances. As such individuals may have been at risk of either not being able to provide fully informed consent (Fumiyo et al., 2009) or, if able to consent, may be more likely to be damaged by the process of involvement.
- The interviews were predicted to provoke an emotional response by some participants. This was an inevitable consequence of intentionally requesting that individuals describe this particular experience. My extensive history of working with precisely this client/family group provided me with professional experience that I was able draw to on to minimise the risk of harm. I aimed to

ensure that interviews ended constructively with a focus on what has “worked” for that individual, what their strengths are and identifying where and how they seek support. Written information and signposting towards relevant and freely available support services were also left with each participant. It was planned that interviews were to be terminated if they proved too challenging and the end of the encounter would be therapeutically managed.

- Experience shows that family members not in contact with specialised services rarely have their difficulties acknowledged, their story heard and the professionals that they meet are unlikely to be brain-injury aware. It was predictable that participants would ask for help, advice or assistance directly from me. It was necessary for me to establish my role clearly with the participant, providing information and signposting but defining the limits to my potential involvement.

Data Security

All data was held according to the requirements of the Data Protection Act 1998. It was highlighted on the survey that respondents could withdraw at any time without giving a reason.

Ethical approval

My research proposal was considered a “high-risk” endeavour as defined by the University of Sussex research governance committee framework and accordingly underwent the appropriate level of ethical review. Ethical approval for this research was granted on the 14th April 2014, reference ER/MH373/1, approval certificate (appendix 2).

3.13: Researcher positioning and reflexivity

Reflexivity as a concept is subject to some debate with authors noting that the word appears to have different meanings and can be used, at points, interchangeably with the phrase ‘critical-reflection’ (D’Cruz et al., 2007). D’Cruz et al endeavour to provide clearer definitions of these varying meanings, identifying three variations in meaning. The second of these is the version that applies to my understanding of the phrase and

its usefulness with regards to qualitative research. They note that reflexivity in this context is characterised by:

Critical awareness of self, reflection-in-action, knowledge as social construction, situated knowledge, ambiguity about generalizability of knowledge, uncertainty.
(D'Cruz et al., 2007)

Studies of social worker researchers' use of reflexivity identify no structured systematic use of such tools or actions but note that the nature of reflexivity, in this context, may relate more to researcher attitude towards their work (Probst and Berenson, 2014).

I have taken reflexivity in its simplest form to mean the development of the skills that support awareness of what influences the creation of knowledge, both in a structural and personal sense (Sheppard et al., 2000).

The DSW course at the University of Sussex is specifically aimed at supporting experienced professionals to engage in research, developing the "insider" or near-insider perhaps. Whilst this may bring advantages to research it also brings with it potential risks in relation to where the researcher positions themselves in relation to the research, the biases inherent in insider status, and the motivation for undertaking the research affecting and creating what is found (Drake, 2010). The long-term experience of the professional when combined with their more novice researcher role potentially biases the outcome via a *déformation professionnelle* or occupational hazard. As has been noted "if all you have is a hammer, everything looks like a nail" (Maslow, 1966, p.15).

I recognise therefore that I am not neutral within this research, my questions are shaped by my experience and interests, and these same factors will influence the analysis and themes identified. I have therefore written in the first person throughout and not referred to myself as "the researcher" as this would be disingenuous and inaccurate in my case (Webb, 1992). I have instead taken as a stance that my

experience, my knowledge base, my beliefs and values will inevitably influence the questions that I ask and the interpretation I place upon the data generated by the research (Sword, 1999). To help guard against my inherent biases dominating and removing the “plausibility” of the research (Koch and Harrington, 1998) I have been careful to recognise my position and build in safeguards.

I am aware of the need not to discount the views and comments of relatives who present a different picture to the one I have experienced over my career. Failure to take account of the views and information provided by individuals who may challenge my preconceptions runs the risk of negating their experience. By including an online survey, one that allowed for open-ended responses, as well as rating scales, the research was able to gain a greater breadth of respondents and increased richness and detail in the content of the information provided, perhaps pointing towards more authenticity, generalisability and authority. Control for the content, what the respondents wrote, was therefore left with the respondent. Whilst the potential for bias in the development of the thematic analysis is unarguable, the use of an approach as espoused by Braun and Clarke (2006) supports greater transparency by promoting logical consistency and clarity (Schutz and Natanson, 1973).

Whilst I have worked in the field of ABI for many years and have worked continuously alongside some brain-injured individuals and their families for up to 18 years, I am not an “insider” in the sense that I do not have a very close relative with an ABI. I do have friends, neighbours and more distant relatives who have had mild to moderate brain injuries but I am not the partner or parent of a very severely brain-injured person. I have more than a passing knowledge of the subject matter, particularly when compared to a researcher totally new to the topic, but my role, as understood by those I interviewed, was of an interested professional turned researcher.

This lack of complete “insider” status may be perceived as having some advantages, such as raising the status of the interviewees to that of expert (Berger, 2015), whilst

my familiarity with the subject matter (and its often highly emotive nature) alongside my knowledge of practice and the often devastating impact of ABI, provided me with a common language and, I perceive in hindsight, the quick development of confidence in me by the interviewees. In a positive sense this confidence and common language enabled interviewees to speak openly about the impact ABI has had upon them, upon their relative and upon their relationships. A number of interviewees discussed very private and in some cases intense matters of love, of anger, feelings of hatred and/or despair, as well as their perceptions of their own failings and inadequacies. Potentially less positively the shared language may, upon occasion, have lead to an explicit or implicit decision to leave things unspoken by the relative, a decision informed by the view that as I would “already know” what the relative had experienced and so it could remain unsaid.

To support my own reflexive thinking (Berger, 2015) I have actively used my academic supervision and also my peer group of fellow doctoral researchers. The structure of the DSW at the University of Sussex is such that, from year three onwards, the majority of the face-to-face contact is focused upon peer presentation and debate, facilitated and informed by academic staff. On three separate occasions I have picked up on comments made to me and incorporated this within my sense of my own positionality within the research.

On one occasion, prior to undertaking the interviews, I expressed concerns to my peers that the interviewees may want more from me than I was able to provide. My professional role involves working alongside brain-injured people and their families to identify difficulties, work towards structuring solutions and facilitating adaptation to very changed circumstances. I was aware that this would not be my role with the interviewees and that it would simply not be possible for me to support family members in a way that I perceived I might be requested to do. I was concerned that this may be the expectation some interviewees had of me and I was troubled ethically by the thought of walking away having not met these expectations, knowing as I do how lacking in support the relatives of brain-injured people often are. One of my fellow researchers highlighted to me that I was imagining myself at interview in a

professional mode when in fact the interviewees only knew me as a researcher, that all the correspondence and expectation contained within was clear on this point. Experience of undertaking the interviews proved this to be the case as whilst, to varying degrees, individuals did ask questions, ask for advice or contact details of organisations, I was not placed in the position of being the responsible professional. My colleague had been correct and I was able to reflect upon this and position myself more clearly as a researcher and not a practitioner.

On two further occasions, during academic supervision, brief comments have resonated with me and informed the research. Firstly whilst considering what to research I was advised that, as the work would be with me for some time, it is necessary to choose to undertake research that would continue to motivate me; the research questions had to appeal to my intrinsic motivation. This enabled me to pick the subject and questions that I did. Up until this point I had been focused, at least in part, upon what my more quantitatively minded colleagues might think about my research and how a lack of highly detailed statistical analysis would impact upon their views. Having completed the research I am now more comfortable with the value of the findings, of the veracity of the narratives gathered and integrated.

I was also reminded in supervision that I should be prepared to be presented with opinions and experience that challenged my views, that I might not like what I hear. More experienced researchers may take as evident each of these three comments but for me they were key in supporting my developing sense of where I was positioned within the whole undertaking. Whilst a Doctorate is necessarily an endeavour for an individual, the knowledge and experience of others has been vital for me throughout.

3.14: Ethics in Practice

Online survey

As previously noted, a number of people who were relatives of people with other neurological conditions and a number of brain-injured people completed the survey. The data from these completed surveys was excluded as it was neither allowed for in terms of the ethical agreement reached with the University of Sussex nor was it co-

terminous with the research questions, aimed as they were at the relatives' experience of ABI.

Interviews

As was predicted, the process of interviewing relatives of people who had suffered life-altering injuries provoked an emotional response from virtually all of the interviewees to varying degrees.

Participants often became upset when discussing:

- The accident/incident that caused the brain injury, the experience of being informed of this and the early days in hospital.
- The loss of future/of potential experienced by the relative with a brain injury.
- The respondent's own losses and grief for these losses as a consequence of their changed circumstances.
- The impact of the brain-injury on siblings or children of the person with a brain injury.
- The respondent's ambivalence regarding their view of the nature and value of the life lived by the relative post-injury.
- Frustration at services, family and/or the wider society for not seeing, understanding or responding to the injury, in particular the non-visible aspects of it.
- Fears and anxieties for the future, in particular if the participant pre-deceases the person with the brain injury.

As planned the interviews were ended positively with reference to the participant's resilience and support to their injured relative. I thanked the participants at this point (and again later by email) and the majority stated that they were pleased to be involved for their own benefit and if this could help others in their situation in future. I believe that duration of interviews and the extremely difficult and private content

covered openly was indicative that the relationships developed between the participants and myself were warm and respectful.

Towards the end of the interview process I acknowledged the resilience of participants and asked what it was that they did to look after themselves, in particular how would they look after themselves immediately following the interview. I sought to explicitly enable the participant to state what it was that they would do following my departure.

After the interviews a number of participants offered me meals and even accommodation. Though I did not accept, this suggests that the process was bearable for them and that the brief relationships developed were positive.

I adjudged that two participants required a more thought-out and therapeutic end to the meeting. Both participants were wives of men who had been more recently injured and neither of whom had yet managed to return from specialist care settings to the community by the time of the interview. Both women appeared to need (and were provided with) reassurance concerning their situation, more directive signposting to where they may find support, and an acknowledgement that their story had been heard and recognised as one that was very challenging and that they were doing the best that they could. Whilst this was provided in particular to these two individuals, all the interviews were ended on a constructive note. A possible benefit of near-insider researcher status and a lengthy history of working with family members of brain-injured people was having the confidence and experience of managing highly charged and emotional situations that enabled me to do so.

The following excerpt is taken from an interview with the mother of a man who had his first brain injury more than 25 years previously. I have included it here as an example of the therapeutic ending to interviews and as a demonstration as to why the ethical considerations for this research were required and were central to the research, not a needless addition or a distraction from it. The last sentence was not finished but left unspoken, names have been changed.

Interviewer: I'm aware that today's been quite upsetting, what will you do today? This is for me. What will you do today just so that I can know that you're -?

Participant: I don't dwell. I, over the years, have learned not to do that. I don't go over and over. I've been through that and some of the things that we've talked about are traumatic but it's just at a level that I can quite easily cope with, and when you've gone it's gone.

Interviewer: Okay. I can be reassured of that?

Participant: Yeah, definitely. I've had to learn how to do that. There's nothing unresolved. If I want to cry now because something's upset me with Peter it happens and that's it.

Interviewer: Okay. It must take some time to learn that and some pain?

Participant: It is a lot of pain to learn that, yeah. It's okay that... I don't... yeah, it's okay to grieve really and not expect that "That's it, it's finished" because it never is. Every time Peter gets a disappointment it's...

3.15: Data Analysis

Online survey

The quantitative data generated by the survey was collated initially on Excel prior to being exported to a data analysis tool. The results of the survey were collated and organised in SPSS (version 24). SPSS is a statistical package produced by IBM that is widely used within the social sciences (Field, 2000). The intention of undertaking this procedure was to identify if any correlations can be found between the results; at its most basic, does the data support or discount any hypotheses concerning the respondents' reports, and are patterns of results identifiable?

The qualitative data generated by the survey was examined to look for commonality and repeating themes as well as differences.

Interview data

The transcribed interviews were coded using NVivo, a computer-assisted qualitative data analysis package. The coded data was subjected to an Inductive Thematic Analysis (ITA) to develop the themes later described. As a technique, this approach offers a means of ensuring the researcher engages hermeneutically with the interview data, without imposing his/her own readings too prematurely on them. This analysis method therefore provided a framework that was useful in engaging with what critical realism calls the 'experience' level of reality, before extending that analysis through abduction to the underlying mechanisms that shape it. However, that said, the term 'inductive' belies the fact that all thematic analysis is an act of interpretation (Braun & Clarke, 2006), and in this case my analysis was rooted in the assumptions set out in sections 3.1 and 3.2. In particular, the 'bio-psycho-social' theory which I bring to bear on the interview data led me to classify the themes with an awareness that all three dimensions impacted on my informants.

Short phrases, whole sentences or paragraphs were isolated from the body of the original transcripts and categorised depending upon explicit semantic content. The content was therefore categorised into what the NVivo programme describes as "nodes". A node is defined as a collection of data with common areas of interest or material that is related. For this research I did not use *a priori* coding but defined codes for the text and assigned text to nodes as the analysis proceeded. Sub-nodes and even sub-sub nodes were created as examination of further material allowed a more nuanced reassessment of initial coding. As an example, many instances of what may be categorised as "Acquired brain injury related needs and changes" were discussed at interview and labelled under this node during analysis. A subset of this category developed, what may be defined as "difficult behaviour" and this was divided further into "difficult behaviour in the community" and "difficult behaviour relating to lack of insight". (See appendix 5 for the full list of nodes, sub-nodes and sub-sub-nodes)

The nature of the software package used (NVivo10 for Mac) supported this process by providing little opportunity for a researcher to see much more than a sentence or two of text at any one time. By decontextualizing the transcript material the content

becomes easier to view in isolation from the whole, supporting identification of repeating words, phrases, ideas or concepts across subjects (Braun and Clarke, 2006). This makes coding more mechanistic and laborious (perhaps) but potentially reduces the opportunity for researcher bias (or short-cutting to themes) by increasing objectivity as data is coded/labelled (ascribed to a node or nodes) on a line by line basis with less of a context to inform or guide decision making (Guest et al., 2012). Such an approach however runs the risk of losing meaning, sense and context, so essential to the critical realist analysis, under the guise of imposing claimed objectivity. Therefore my focus in looking for themes was to look both at the broader pictures and stories told as well as the disembodied phrases and nodes they created, to ensure that a context was maintained. Such an approach recognises the value of narrative in health and social research, placing it as an equal party to quantitative approaches (Greenhalgh, 2016). Having undertaken the initial phases of the analysis, a more global reading of the interviews and interview narratives was therefore undertaken. This allowed a broader reading of data (and the results created) to be reintegrated into what the earlier stages of the ITA process may have made disjointed. Undertaking the analysis in this manner maintains the continuity of the individual accounts and was done so to counter the potential of ITA to fragment data (Braun and Clarke, 2006, p27). This then allowed for patterns in the data to be identified that were not visible upon first review. Such an approach abductively informed the development of the seventh theme described in chapter 5 by linking the more global reading of the narratives with narrative theory as described by writers such as Charon (2006) and Mattingly (2010).

The perceived benefit of using this form of analysis is to create themes and patterns that repeat across the data, enabling different experiences to be collated when commonality was developed.

As such the volume of information, the richness and variety of data, is rendered more manageable for the creation of a more easily described experience, despite the highly personal and individual nature of it. As a practitioner with an eye for the need for research to have a practical application, I chose this form of analysis as the one that I hoped would best be able to resonate with colleagues whilst not losing contact with

the meaning of the lived experience of the participant, in an attempt to move from the anecdotal to the plausible.

While anecdote is rightly placed at the bottom of the evidence hierarchy in evidence-informed medicine, narrative research should not be equated with anecdote any more than quantitative data should be equated with truth. Epidemiological studies and trials help us to make predictive statements about the frequency of events in populations and the likelihood of particular outcomes; narrative research helps us to make sense of experience. Both can be done well or badly and produce findings that are more or less trustworthy (Greenhalgh, 2016, p.5).

In NVivo the individual data are identified, coded and stored within the programme at “nodes”. Naming of nodes was an iterative process with sub-nodes (and sub-sub-nodes) developing over time as similarities and subtle differences were identified within the transcripts. Virtually all the output from the participants was coded into at least one node, albeit some was not crucial for this particular analysis as some of the material was focussed upon introductions, explanations regarding the research project, information exchange, pre-amble and conversation to respectfully support the development of the research relationship (Seidman, 2013). Whilst potentially essential for participant comfort and engagement, the content created thus sits outside of the focus of this research.

As the interviews were semi-structured and the participants had been provided with information regarding the nature of the research, some topics were pre-determined to a degree. Thus specific questions such as “how did you find out about the brain injury?” were put to participants who did not volunteer this information without being asked. This in turn lead to text, in this example, being coded as “early days, family coping” or “finding out about the accident/injury”

A full list of the nodes generated, the number of individual participants (n=16) who provided data that fitted that code and the number of individual data segments for each code is provided in appendix 5.

Use of computer programmes such as NVivo lend some credence to qualitative researchers endeavouring to demonstrate greater validity and reliability with data (Guest et al., 2012). Exponents of the programme identify the possibility for it to ensure an audit trail is made possible (for examiners or others to inspect if required) and a more transparent picture of the data to be created (Welsh, 2002). However, this should not equate to or be comparable with relying upon numeric output (frequency of data being ascribed to particular nodes). Such an approach runs the risk of missing meaning within the words used by participants and ascribing equal value to each piece of data, what is described as a 'frequency bias' (Lu and Shulman, 2008). Others have criticised the potential for such an approach preventing the more novice researcher from being able to step back and view the data as a whole, being unable to see the "wood for the trees" (Johnston, 2006). NVivo and other data analysis tools can be used to support the structuring of work, particularly when the dataset is large (or large for a single researcher) (Guest, 2012).

An inductive thematic analysis, in the context of a mixed methods approach, enables triangulation between the qualitative and quantitative results of the study with the pre-existing literature to generate "completeness" and provide "confirmation" (McEvoy and Richards 2006), revealing different facets of reality for the family members. The quantitative results provided more easily observable patterns whereas the qualitative results generate a greater sense of the experience and insights into how the interactions between contexts and mechanisms might generate the outcomes, in line with the aims of the research.

3.16: Identification of themes

The process of identifying themes in the data, as described by Braun and Clarke amongst others (Braun and Clarke, 2006), was informed by re-reading of the

transcripts and the data, codified in NVivo, by identifying repetition within and across the individual nodes, by collapsing nodes with common subject matter, idea or content and by close reading of the individual and collapsed nodes.

In this process themes are identified as being broader than the nodes that form them. It is an iterative process of defining and reviewing themes by returning to the nodes and data that formed the nodes to examine for logical consistency. Refining the themes supported them to develop in a manner which identified and allowed for the construction of their boundaries and their rationality, whilst accepting some overlap between themes is inevitable. To support this process the nodes and sub-nodes were printed onto paper to facilitate their physical movement and mapping visually (Braun and Clarke, 2006). This is a time consuming process of checking and re-checking that the content of the nodes, the data, supports the theme coherently.

The themes themselves did not “emerge” from the data without my own interpretation; in this sense inductive thematic analysis is not a passive process. Rather the analysis of the data creates the links that facilitates their construction (Ely et al 1997).

Six distinct but interlinking themes were identified inductively by this process (Joffe, 2012, Alhojailan, 2012, Fereday, 2008) and are described in chapter 5. A further overarching theme (inductively developed from the data, abductively linked to the literature) is also described in chapter 5.

The first four themes have a degree of linear progression as relatives described their experience and development of knowledge, their involvement in the life of the injured person, the impact this has upon them in a personal sense and the unavoidability of their input prior to the themes bifurcating around the point of negative or positive experiences of support. (See table 19 for diagrammatic representation of themes)

The overarching theme, whilst derived during the inductive thematic analysis process, developed at a slightly later stage when reconsidering all of the interviews in their

entirety. Reflecting upon the family member's accounts in their totality supported the identification of this. The overarching theme, *the relative as curator of narrative*, was less apparent in the direct semantic content and is more an interpretative account of the process. This theme could only develop after the event when considering the interviews together in the context of themes that they created.

3.17: Overall Analysis: integration of literature, quantitative results and inductively derived themes

The results of the literature search (chapter 2) informed the questions that formed the online survey (chapter 4). This in turn led both to the questions asked in the semi-structured interviews and to the creation of the inductively derived themes that these interviews helped form (chapter 5). This supported me to answer the first two of my research questions, namely:

- What is the experience of family members when a relative suffers an acquired brain injury?
- What is the experience of family members of the services they encounter as a consequence of their relative's acquired brain injury?

but did not allow me to answer my third question, that which for me as a practitioner has equal importance:

- How can social work/professional practice best be informed by the experience and knowledge of family members?

In order to do this I needed to revisit the literature in light of the themes and the quantitative and qualitative data from the online survey and link these results coherently to abductively reasoned answers. This was undertaken in recognition of the need to commence with the process of ITA to provide a faithful account of the relatives' experience via an inductive approach. However for this to be able to link theory to practice it was necessary to go further than this, abduction, as a process,

allows for theorisation beyond the immediate experience. This approach accommodates a researcher's pre-existing theoretical knowledge and provides the starting point for the development of more abstract theory (Oliver, 2011, Charmaz, 2006).

A mixed methods critical realist approach is described as enabling a focus upon understanding and explaining structures and mechanisms (McEvoy & Richards, 2006). The context within which the research is carried out is recognised as important (Pawson & Tilley, 1997) and such an approach is noted to facilitate the integration of multiple narratives (Maxwell 2004).

To utilise the themes and quantitative results from this research it was necessary to triangulate this against the literature to derive theory-related explanations (Modell, 2009). In doing so, the quantitative and qualitative data and resultant themes are reinterpreted and placed in the context of the concepts described by the literature. This process of abduction supports a realist explanatory theory of the individual relative's experience and provides a framework by which practitioners may be better supported to understand and act upon this understanding (Råholm, 2010, Eastwood, 2014). Abductive reasoning runs significant risks of flawed logic leading to fallacious conclusions and theory development, belief formation leading to belief justification. To counter this, abductive supposition is noted to be needed to be supported by inductively derived evidence (Lipscomb 2012).

Chapter 6 is the synthesis of the work, providing a theoretical framework by which to contextualise the relative's experience in order to answer the question relating to professional practice.

Chapter 4: Online Survey: Analysis and Findings

The completed surveys were analysed both quantitatively and qualitatively to identify both potential correlations from the numeric/rating scale responses and to begin to identify repeating themes and patterns developed from the questions that had provided opportunities for narrative responses. In this chapter I initially identify the quantitative data before moving on to the qualitative responses.

A total of 110 surveys were completed online and fully enough to be considered for analysis. Other survey responses were discounted if they did not meet the criteria established.

4.1: Results – Respondent descriptors

As can be seen from the blank survey in appendix 3, descriptor information was collected pertaining to both the respondent and the person with an ABI they reported upon, here referred to as the PwBI (Person with a Brain Injury).

Table 1: *Gender of respondent*

	<i>Frequency</i>	<i>Percentage</i>
Female	93	84.5
Male	17	15.5
Total	110	100%

Table 2: *Age of respondent*

	<i>Frequency</i>	<i>Percentage</i>
18 to 24	4	3.6
25 to 34	5	4.5
35 to 44	19	17.3
45 to 54	41	37.3
55 to 64	26	23.6
65 to 74	13	11.8
75 plus	2	1.8
Total	110	100%

Table 3: *Relationship of respondent to the PwBI*

	<i>Frequency</i>	<i>Percentage</i>
Parent	38	34.5
Grandparent	1	0.9
Partner	15	13.6
Spouse	29	26.4
Brother	1	0.9
Sister	8	7.3
Child of injured party	6	5.5
Friend	8	7.3
Other	4	3.6
Total	110	100%

68% of respondents were either parents of or partners of the injured party and 74.5% were aged 45 or above.

4.2: Results – descriptors of the brain-injured party (PwBI):

Table 4: *Gender of PwBI*

	<i>Frequency</i>	<i>Percentage</i>
Female	25	22.7
Male	85	77.3
Total	110	100%

Recent increases in rates of injury amongst females in the England and Wales currently indicate that men are now 1.6 times more likely to be injured than women. There has been an increase in incidence of injury amongst females since 2006 (Headway, 2015b). Notwithstanding this, the predominance of female respondents reporting upon injured males in the survey was considerable.

Table 5: *PwBI age at time of injury*

	<i>Frequency</i>	<i>Percentage</i>
11 – 18	3	2.7
19 – 25	12	10.9
26 – 35	22	20
36 – 50	35	31.8
51 – 65	29	26.4
66 plus	9	8.2
Total	110	100%

Nearly 90% of the cohort described by respondents were of working age at the time of injury which would indicate that two specific groups, known to suffer higher levels of incidence of ABI, are under-represented, children and those aged 75+ (Trefan et al., 2016, Thompson et al., 2006). Older people are noted to have worse outcomes from ABI (Merzo et al., 2016) whereas some younger people with an ABI are noted to suffer significant consequences across the lifespan (Sariaslan et al., 2016).

Table 6: *Cause of injury: Trauma vs Non-Trauma*

	<i>Frequency</i>	<i>Percentage</i>
Trauma	77	70
Non-trauma	33	30
Total	110	100%

Table 7: *Cause of injury: Mechanism of ABI*

	<i>Frequency</i>	<i>Percentage</i>
RTA: Driver/Passenger	31	28.2
RTA: Pedestrian	12	10.9
RTA: Cyclist/Motorcyclist	17	15.5
Assault	8	7.3
Fall	9	8.2
Stroke or Brain Haemorrhage	17	15.5
Viral illness (Meningitis or encephalitis)	4	3.6
Anoxia/Hypoxia	6	5.5
Other	6	5.5
Total	110	100%

Road traffic accidents account for just over 50% of the respondent cohort, in line with other research into mechanism of injury (UKABIF, 2016).

Table 8: *PwBI living status: Community vs Non-Community setting*

	<i>Frequency</i>	<i>Percentage</i>
Community	95	86.4
Non-Community	15	13.6
Total	110	100%

Table 9: *Years since injury*

	<i>Frequency</i>	<i>Percentage</i>
2 to 5 years	42	38.2
6 to 10 years	28	25.5
10 years plus	40	36.4
Total	110	100%

It is identified in the literature that there are few longer-term follow up studies (particularly 10 years + post injury) and that there are significant issues with researching this group, the more severely injured, many of whom are more likely to be “lost to follow up” for researchers (Dan Hoofien, 2001, Langley et al., 2010). It was therefore pleasing to have more than a third of the cohort reporting over ten years experience post-ABI.

Table 10: *PwBI Living Status: Type of accommodation*

	<i>Frequency</i>	<i>Percentage</i>
PwBI lives with respondent	45	40.9
PwBI lives alone	15	13.6
PwBI lives with other family, partner or friends	14	12.7
PwBI lives alone with paid support	21	19.1
PwBI lives in rehabilitation setting	4	3.6
PwBI lives in residential or nursing home setting	8	7.3
Other	3	2.7
Total	110	100%

UK census results into household composition indicate that fewer than 12% of people of working age live alone whereas 32.7% of this cohort, who live in the community, do not live with friends or family (ONS, 2011).

Table 11: *PwBI employment status*

	<i>Frequency</i>	<i>Percentage</i>
Full time, open market	4	3.6
Part time, open market	7	6.4
Sheltered employment	2	1.8
Voluntary work	15	13.6
Does not work	78	70.9
Other	4	3.6
Total	110	100%

Results of research into rates of return to work following ABI vary according to methodology. A systematic review of such research identified that 40% subjects were able to return to employment within a two year period following injury albeit sometimes at a lower level or for fewer hours than pre-injury (van Velzen et al., 2009). This figure is replicated in other work that includes those with moderate and severe injuries (Friedland and Potts, 2014). Ability to return to (and maintain) employment is noted to be a function of behaviour, cognitive/functional abilities and communication abilities and style (Brooks et al., 1987, Meulenbroek and Turkstra, 2016).

With a paid employment rate of only 10% it would suggest that the cohort in this study are more severely injured than in some of the research relating to employment albeit sampling may account for this.

4.3: Respondent rating of difficulties as a consequence of the ABI

As can be noted from the survey (appendix 3) respondents were asked to rate their view of the relative difficulties experienced by the individual they were reporting on, from 0 (friend/relative has no issues within this domain) to 10 (friend/relative has extreme difficulty). The rating scales were split into different domains that reflect the commonly experienced difficulties after brain injury; these were titled executive, behavioural, emotional, physical, sensory, cognitive and insight difficulties. An explanation of each domain was provided to support the judgement of the respondent. Not every respondent answered yes/no for these rating scales; a “do not know” option was available, hence frequency of report is not 110 for each scale.

Histograms were produced to look at the distribution of the respondents' scores. The data was not normally distributed and therefore non-parametric statistics were employed. Whenever data does not comply with the assumptions of a normal distribution the most suitable measure of central tendency is the median, as the mean and standard deviation rely upon the data being normally distributed (Boddy and Smith, 2009, Field, 2000).

Table 12: *Frequency of report by domain of difficulty*

	<i>Frequency of report:</i>	<i>% reporting this issue</i>	<i>Median</i>	<i>Mean</i>	<i>Std. Deviation</i>
Cognitive difficulties	108	96.3%	8	7.34	1.958
Executive difficulties	110	92.7%	7	6.65	2.687
Emotional difficulties	106	83.6%	7	5.94	2.966
Behavioural difficulties	106	75.4%	6	5.36	3.387
Insight difficulties	104	66.3%	6	4.88	3.749
Sensory difficulties	106	56.3%	3	3.47	3.423
Physical difficulties	107	56.3%	3	3.70	3.910

Respondents reported that invisible difficulties, such as cognitive and executive impairments, were rated as more extreme than physical impairment. As would be expected from practice, physical impairment is the domain with the fewest number of people affected and the lowest average rating. Although only 56% ($n=62$) reported physical difficulties to be an issue it should be noted that twenty-two reported very high levels of physical impairment (15 reporting 10/10 and 7 reporting 9/10). Recent research into the effectiveness of decompressive craniectomy for traumatic intracranial hypertension (the removal of large sections of the skull post trauma to prevent secondary damage by increased pressure) has identified that the procedure does significantly reduce mortality but does not increase the proportion of those who go on to make good recoveries; individuals are more likely to be left in a persistent vegetative or very severely disabled condition (Hutchinson et al., 2016). This and other

advances in neurosurgical procedures would appear to be increasing the possibility of severely injured people surviving but without necessarily improving outcome greatly or at all (Garvin et al., 2015), at least for some.

It is the invisible difficulties that are more regularly reported and are rated as predominant. In particular cognitive difficulties were noted by over 96% of the cohort. This was rated as the issue that creates the most difficulty for the person with the ABI. This would indicate that the cognitive, executive, emotional and behavioural difficulties were experienced as being the main ones, with 66% having this compounded by reduced insight.

Previous research has shown that insight difficulties are associated with increased use of case management time, greater difficulty for family members and difficulties engaging the brain-injured party with rehabilitation (Clark-Wilson et al., 2016, Bach and David, 2006, Medley and Powell, 2010). Therefore, this study looked for relationships between the different domains and insight. Non-parametric Spearman's Rho Correlations (non-parametric test) were performed between insight and each of the domains. Table 13 shows the correlation coefficients for each of the tests. It can be seen that all measures, with the exception of the physical scale, showed significant correlations with reduced insight.

Table 13: *Correlations between domain of difficulty and reduced insight*

	Executive scale	Cognitive scale	Behaviour scale	Emotion scale	Sensory scale	Physical scale
Insight Scale	.535**	.493**	.346**	.302**	.216*	.187
Sig. (2 tailed)	.000	.000	.000	.000	.030	.060
N =	104	104	100	100	101	102

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

These results are in line with experience from practice where loss of insight is more likely to be associated with executive, cognitive and behavioural impairments, with individuals least likely to demonstrate an understanding of their problems with idea generation, planning, decision-making responding to feedback in the moment, etc. These issues and how they presented difficulties for the relatives of the person with the ABI are developed further in later chapters. It is of note however that it is not physical impairment that is correlated with such difficulties; invisibility of impairment and the injured party's lack of insight makes the relative's support role and tasks more taxing. Understanding the nature of the difficulty, the underpinning reasoning for post-injury changes, is not therefore obvious and loss of insight reduces or removes the injured person's capacity for accurate self-analysis to support this.

Table 14: *Rate of post injury friendships for both the PwBI and respondent*

Friendships post injury for both the person with the ABI and the respondent, compared to before the brain injury do you/your brain-injured friend/relative have:

	<i>PwBI %</i>	<i>Respondent %</i>
Fewer friends than previously	76.8	49.5
More friends that previously	7.4	9.9
About the same number of friends as previously	15.8	40.6
Total	100%	100%

A social consequence of ABI, loss of friendships, was noted to have occurred for 76.8% of this group but, also, for nearly half of the respondents too. Friendship post-ABI is noted to be an under-researched field but to be one that is problematic for the injured party (Salas et al., 2016). Spearman's Rho correlations were performed between the number of respondents' friendships (loss of) and the different domains. It was observed that increased loss of insight and behavioural difficulties were strongly correlated with loss of friendships by the respondent.

This correlation was not found between the domains and loss of friendships by the injured party. This may potentially reflect the fact that, as is observed in practice, people with an ABI lose pre-existing friendship networks but a few form new acquaintances. Potentially more likely however this may instead be an artefact of the statistics in the sense that such a high number of individuals are reported as having lost friends that analysis of sub-divisions of who is more likely to do so does not generate specific correlations.

Table 15: *Correlations between domain of difficulty and reduced friendships for the respondent*

	Insight scale	Behaviour scale	Executive scale	Sensory scale	Emotional Scale	Cognitive Scale	Physical scale
Respondent Friendships	.327**	.310**	.228*	.227*	.215*	.128	.098
Sig. (2 tailed)	.001	.002	.023	.024	.036	.204	.339
N =	96	96	100	99	96	100	98

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

These results would indicate that, for this cohort, there is a significant relationship between increased difficulties with behavioural control and loss of insight by the injured party, and the friendships of the non-injured relative. This relationship is not seen between the injured party's physical impairment and the respondent's friendships. Again it is the invisible deficits and difficulties that appear to be having a greater impact upon the respondent than purely physical disability.

Table 16: *Respondent rating of the services received by the brain-injured party as a consequence of the brain injury*

Respondents were asked to rate, out of 10, the quality of the service received by the brain-injured party. Frequency of report varies as not all individuals access every service.

	<i>Frequency of report:</i>	<i>Percentage reporting using this service:</i>	<i>Mean quality score</i>	<i>Std. Deviation</i>
Brain Injury Case Manager	44	40%	7.6364	2.08082
Hospital (accident and emergency, intensive care, high dependency unit or neurosurgical unit)	93	84.50%	7.0215	2.40912
Neuropsychologist or Psychologist	66	60%	6.8485	2.10671
Support service such as Headway or CBIT	75	68.20%	6.8	2.371
Physiotherapist	69	62.70%	6.6667	2.10508
Occupational Therapist	69	62.70%	6.2464	2.24529
Average satisfaction			6.157	
Neuropsychiatrist or Psychiatrist	46	41.80%	5.8696	2.23715
Counsellor	33	30%	5.8485	2.51398
Day Centre	27	24.50%	5.4815	2.7227
Inpatient rehabilitation (either NHS or other provider)	76	69.10%	5.3947	2.98476
Speech and Language Therapist	51	46.40%	5.3529	2.4562
Home care or support work services	64	58.20%	5.1875	2.52527
Social Worker/Social services	59	53.60%	4.5254	2.89087

As was echoed in the written comments by participants, emergency and intensive care hospital treatment was rated highly. The service does, quite literally, save the life of the injured party and hence this is perhaps unsurprising. Review of the data from the completed surveys and the interviews identifies an error in the method. Whilst family members were almost universally positive and grateful regarding the treatment received during the emergency phase, reports of treatment once the injured party had been discharged to more general wards were much less favourable. Many instances of very poor practice were reported, as was potential medical negligence. This apparent dichotomy between the high quality and valued emergency intervention and the apparent failings on non-specialist wards was not highlighted in the above table owing to a failure to have, as an option, “general hospital ward”.

Once an individual’s risk of imminent death had been averted a range of services (or potential services) become a possibility depending upon clinical need and availability. As can be seen from table 16 the highest rated services are those that may be characterised as specialising in brain injury. Such services frequently work across settings and have as a focus restoration of functioning. It is notable that the highest rated services also have the lowest standard deviation scores indicating that the individual data are more likely to be concentrated around the mean.

Whilst it would be unwise to infer too much from data generated from an online survey of self-selected participants (unless similar results could be replicated with other cohorts of relatives) the difference in rating for brain injury case managers vs. social workers is stark and would appear not to have previously been investigated.

4.4: Results: Commentary and narratives from the online survey

The provision of questions enabling a free-narrative response provided valuable and rich data.

Anonymity of respondents and their family members has been protected by the development of the key below. Named professionals are referred to solely by their job titles and named towns/cities have been replaced with “the city” or “the town”,

named services or hospitals are simply referred to as “hospital” or “rehabilitation unit” etc.

To enable respondents’ comments to be contextualised through the remaining part of this chapter a key has been created consisting of the relationship with and the living arrangements of the injured party and number of years since injury.

Table 17: Key to support identify respondent/PwBI details

Living arrangements:	T = Live together U = Lives in a unit/residential/rehabilitation setting A = Lives in own accommodation, with or without paid support
Years since injury:	02 = 2 – 5 years post injury 06 = 6 – 10 years post injury 10 = 10+ years post injury

So U6, for example, relates a brain-injured person, living in a residential/rehabilitation setting, having been injured between 6 and 10 years previously.

Results have been provided, with relevant quotes, to questions 26, 30, 31, 32, 33 and 34 from the survey.

Q26: *How has your relationship been affected by the brain injury?*

97 survey respondents provided written responses to this, the first survey question eliciting free narrative.

Three respondents replied with a one word answer “no” to this question, implying perhaps that they perceive that their relationship has not been affected at all by the brain injury to their relative/friend. Eight individuals noted that they did not know the PwBI prior to the brain injury and hence their relationships were formed subsequently and therefore not changed by injury.

Perhaps surprisingly three individuals replied to question 26 identifying only positive changes to their relationship with the PwBI:

- *It has brought us closer as we now appreciate how short life is. (Child U2)*

I note that none of these three respondents lives with the PwBI, all have suffered their injuries more recently, all are described as very physically impaired but with few behavioural difficulties.

19 respondents directly reported clear changes in role, most usually from partner to carer often with increased responsibility for decision-making and with an end or changes to intimate relationships. Other respondents also reported similar significant changes without directly using the same words.

- *Our roles have changed. My role is that of a carer and feels like being a parent sometimes. My identity within our relationship has changed. (Partner T10)*

The issue of the relative/friend being responsible for the PwBI as a result of changes brought about by the brain injury was a further repeating theme:

- *I have had a dependent since my mid twenties. He is not easy to help!! We have maintained him in a home environment for 28 years but at a cost to ourselves. (Sister T10)*
- *No longer feels equal partnership - is all one sided with me needing to give all the time financially, responsibilities, planning relations with the children, grandchildren and socially, communication difficulties as well as anger and tears. (Partner T2)*

The same issue was reported upon by parents:

- *As a parent my role in some ways had changed little, as I have always looked after and cared for my child, albeit she is an adult now, however now she will always need that care and support and will never be independent. (Mother T6)*

Those whose relatives had very profound injuries resulting in ongoing need for 24 hour a day nursing noted the inevitable impact this had upon the relationship.

- *Our relationship ended after it was apparent that no recovery is expected but I still visit her in her care home. (Partner U2)*

Many respondents noted that the behaviour and needs of their brain-injured relative/friend had a profound impact upon their relationship, one that was exacerbated by lack of insight and/or lack of ability on the part of the PwBI to empathise or reciprocate.

- *I am not his first source of support in times of trouble, so I don't get to help and sometimes I don't even know despite living in the same town. He is not able to initiate contact so if I am unwell I have to keep updating him myself - he appears not to care though I know that is not the case. But out of sight out of mind. I have to work to maintain contact. (Mother A10)*
- *Our relationship with our son has been greatly altered - also tested to the limit, and indeed beyond I think. We walk on eggshells now. He now has mental*

health difficulties, which we are told were brought on by the brain injury. He has tried to kill himself many times and he has also believed at one point that he needed to kill us and then himself. He is not the same person any more, but he is still my son. (Mother A10)

Despite the (usually) unwelcome changes that brain injury brought some respondents noted a process of adaptation that they had been integral to and that some positives could be drawn from this.

- *My son is more reliant on his family and is dependent on us, but it has brought us closer. (Mother T10)*
- *We have had to make compromises. My partner needs a sleep every day. My partner used to book holidays and be in charge of our finances/ bills etc. Our roles in our relationship have changed and shifted, it has strengthened our relationship even though at times it is difficult. (Partner T6)*

For some however it is noted that the change in relationship has a significant impact upon the non-brain-injured party as they experience a loss.

- *I have lost my closest friend and husband, I work daily on his rehabilitation to give him/us the best chance of a happy life (albeit a different one); but he is now a person I care for and share my home with, not my 'husband' - we also have a small child (born pre-injury) and the impact on her life is also hard. I also had to give up my job and I also need to rebuild my life - for all of us! (Partner T2)*
- *Our marriage is very different from before. My husband was very loving & caring & now not so much. [...] I feel lonely in the marriage. (Partner T2)*
- *Relationship is now very strained and has resulted in relative physically assaulting me a number of times. Contact is kept to a minimum. (Father A10)*

Q30 How well did these services include you and your knowledge/experience of the brain-injured party in their work? Thinking about the services you have used, what is the one thing that could have been done differently that would have improved your experience?

Sixty-nine respondents provided a commentary for this question, answers varying from single word replies to the very lengthy. Only three replies would be considered to have been overwhelmingly positive, the vast majority were either mixed or wholly negative.

Positive comments related to use of specialist services such as Headway, independent and highly specialised brain injury rehabilitation units, brain injury case managers and specialist litigation solicitors. Feeling included in the process was also positively commented upon.

- *Since 1998 we have been supported as a family, by the rehab unit. There is a highly professional yet friendly approach to support and understanding.*
(Mother U10)

Negative comments focussed on several repeating areas. These included the impact of the brain injury being missed entirely and neither assessed for nor any services provided; a lack of information given to relatives (most especially at time of discharge); lack of access to specialist rehabilitation; delay (sometimes very significant) in accessing services; poorly planned discharge from inpatient settings; lack of involvement of family in processes; and no overall co-ordination of services.

- *Intermediate rehab unit was extremely poor. Not enough physios or OTs. Nursing and therapy staff did not work as a cohesive team so no continuity possible.* (Partner U2)

The length of time family members were left to cope with no services or non-specialist services was noted by several respondents.

- *We were referred to Headway after 10 years of me coping. Social services did not help up to this point. (Mother A10)*
- *His brain injury was 37 years ago when he was hospitalised, recovered and sent home, no one has ever followed him up. He lived in a home for people with learning disabilities when Mum could not look after him with her failing health..... in the end I went to safeguarding, it was devastating to see him in such a state, neglected and falling, to the point I sat with him in emergency department and refused for him to go back to the care home for learning disabilities. He has since moved into a specialist home and is a different person, he is engaged in activities instead of being confined to his room, he hasn't had a fall in 6 months and is regularly seen by OT and physio. (Sister U10)*
- *We were barely kept informed and given poor information on his discharge so the first few months were a terrible shock and the first couple of years a real struggle. (Sister T10)*

A lack of specialist knowledge or services was commented upon.

- *Local social services were useless at best and got things wrong time and again, no matter what clinical information was given to them. (Uncle A2)*
- *After discharge from ITU he was sent to stroke rehab ward- very ill equipped to deal with the issues and did not provide information. (Partner A2)*

Some respondents noted that they had needed to “fight” to become involved and support their relative/friend.

- *The services did not include me unless I proactively made myself part of the services. (Partner T2)*
- *I was included once I had found the way through to the correct people. The problem was knowing where to start and then being told to contact somewhere else. (Mother A2)*

With regards to respondents' suggestions of what is required to better support them and their injured relative/friend, this too fell into several distinct categories relating the need for accurate information to be provided in a timely fashion, the need to listen to, involve and integrate family into the processes of rehabilitation and discharge, the provision of specialist not generalist services, and the benefit of having an overall knowledgeable single point of contact to co-ordinate services and provide relevant information.

- *Someone to be a go-between from discharge to home who has a knowledge of how discharge works and benefits. (Partner A2)*
- *What was needed was some humanity and sympathetic communication and support but above all accurate info. (Sister A10)*
- *Brain injury case manager from day one as someone needed to coordinate everyone. (Mother A6)*

Involving the family was commented upon by some as making rehabilitation more effective; family being the people likely to implement plans over the longer term.

- *The one thing that should be different - is to recognise that family are the cornerstone of neuro-rehabilitation. If you lose them then you lose the best chance for the person with the brain injury! (Partner T2)*

Overall the responses indicated far greater levels of dissatisfaction with services, in particular with an absence of specialism and/or an entire absence of services and/or information.

Q31: *Were you given the information you needed to understand brain injury and services?*

More than twice as many individuals (42) reported that they were not given information required to understand brain injury and relevant services as reported that they were (20). 14 people replied with a one word answer “No” and 8 with “Yes”.

Of those that did report that they were given relevant information, a number noted that this came via specialist voluntary sector organisations such as Headway, CBIT and the Stroke Association. Others who were satisfied with the information provided noted that this came via specialist services (independent brain injury case managers or neurorehabilitation services) or by their own research. It was notable that a number of respondents reported that the information they needed had to be searched for and that on occasion this took a number of years to acquire.

Some individuals had prior knowledge or worked within health and social care which assisted their search for information.

By independent, voluntary or charity sector:

- *Yes - by the Brain Injury Coordinator of the County. He was brilliant. (Mother A10 - Post no longer funded)*
- *Not until we contacted Headway years later (Partner T10)*
- *Yes. This was provided by Headway and private care. Information from own GP was poor. (Mother A10)*
- *Hospital very poor, Headway very good, Head-First excellent. (Father A10)*

Own research:

- *We were given some information, however did endless research on the internet, read books relating to other injured people & their families experiences. (Mother T2)*

- *No information was given to us by the hospital whatsoever. It was months before he even saw another doctor and I had no idea there were services available to support us until I searched for them myself. (Partner A2)*

Prior knowledge:

- *No, as I had medical knowledge everyone assumed I knew what to do. (Partner A10)*

Good information:

- *Yes have had plenty of leaflets that detail the brain injury and impact to my husband. (Partner U2)*
- *Yes, the rehabilitation hospital in Bath were very good, they gave us leaflets and talked us through it (Sister A6 - Bath Regional Neurological Rehabilitation Unit closed in 2013)*

Poor Information:

- *No not in hospital he was not even on the correct ward that dealt with brain injuries. (Partner T2)*
- *No one sat us down and explained what the brain injury was or which part of the brain had been affected. No one discussed the long-term effects or what we might expect. (Child U10)*
- *No. For social services available, I had none. Few I contacted myself, still was disappointing. I felt no one understood nor aware of "category" Brain Injury. Where autistic, dyslexic and other similar disabilities are known/grouped, I soon became aware that Brain Injury was not known. (Mother T6)*

Respondents far more regularly experienced a lack of relevant information and a need to search for this themselves than the reverse.

Q32: *What are the three most difficult things that you face now as a relative/friend of a brain-injured person, and how well have you been supported to face these?*

Responses to this question were broad but repeating themes were identifiable in relation to the difficulties faced by the respondents.

Some noted functional/behavioural difficulties for the PwBI as a direct consequence of the injury as being the most difficult aspect. Superficial assessments by others, defining a good recovery from ABI being made by an individual's appearance rather than their functioning was also commented upon and criticised by respondents as being an added difficulty that they faced.

- *Anger, frustration and dis-inhibition* (Partner U2)
- *Emotional and behavioural volatility of brain-injured person* (Partner T2)
- *1. Having to do most of his thinking for him. 2. His lack of initiative & motivation* (Partner T10)

Others noted the burden of coping with these changes, particularly when the respondent had other responsibilities or was the only party taking responsibility, and the process of adapting to changed circumstances.

- *Isolation: I don't mean because I am on my own...but unless you live it daily you don't understand how hard it is....and it is hard to articulate this to someone who thinks he is "doing so well" after a 15 min meeting.* (Partner T2)
- *Trying to move on in our life bringing up our 2 children alone.* (Partner U2)

A lack of understanding of the difficulties faced by the PwBI and the respondent by their wider family/friends, by health and social care services and by the wider community, in particular owing to the invisibility of the consequences of ABI, was commented upon.

- *Managing peoples expectations of him- they still think he is the same as he was before. (Partner T2)*
- *Other people's failure to understand that there is a problem. (Partner T10)*

Others noted an absence of adequate/specialist service provision in the statutory sector and/or delays in receiving services. Overall a picture developed of relatives who were left isolated and lacking in information needing to fight for support. Respondents report taking a longer-term view than services.

- *First, second and third, the constant battle for care and support-services is exhausting. (Mother A6)*
- *I need for my husband to start to plan the rest of his life (he used to be a business leader)....there are limited services to help with his insight and ensure that he has a successful life and not one of despair and resentment. (Partner T2)*

Privately purchased specialist services were rated more highly, noted to be supportive of the respondent, knowledgeable about the condition and flexible in response.

- *We have been helped by many of the experts in all three areas and have been very lucky because they have been funded privately. (Partner T2)*
- *By getting the professionals who know about brain injuries involved and having a very good legal team that was able to fight for him helped us to deal with this very upsetting and very emotional time. (Sister A6)*

Some expressed concerns regarding the future.

- *His future will always be a worry especially when myself and my husband are no longer here. I know he has support there if he needs it but I don't know if he will ask for it. (Mother A6)*
- *Knowing my daughter will be on her own when I die. (Mother A10)*

The impact that the injury has had upon the respondent and wider family, including children, was reported.

- *Extreme grief at the loss of my funny, intelligent son (an ongoing never-ending bereavement). (Mother U10)*
- *My mental health suffered - overwhelmed. Had two breakdowns before I got enough help. (Partner T2)*
- *From the children's perspective they always struggle not having the same kind of father their friends have. (Partner A10)*

The PwBI's lack of insight into their difficulties has upon the situation and the impact this had upon the respondent and their responsibilities was highlighted and was an area which exacerbated the respondents' difficulties as self-report by the PwBI and apparent good physical recovery was misunderstood as a genuinely good recovery.

- *Him looking normal, however not being understood by people in authority and others, therefore I am unable to protect him from himself and others. (Mother A10)*
- *Dealing with his altered personality - short fuse on his temper, and no insight into our feelings whatsoever, together with intrusive behaviour and demands for us to do things for him. (Mother A10)*
- *Ill health (but no insight so often at crisis). (Child A2)*

Similarly themes regarding how well respondents have felt supported were identifiable. Some respondents noted that they had received no or little useful support from professionals, the wider community or family.

- *Family who don't understand and they don't understand. A little support but sometimes its like banging my head against a brick wall. (Partner T6)*

- *I do not feel that I have been supported at all. Having to fight for every piece of support or rehabilitation for my husband. No empathy towards us. (Partner T2)*

Whereas a few noted that they had felt well supported by professionals and family. In these instances the professionals concerned were identified as working with the whole family rather than simply the injured person.

- *Brain injury support team has given me tools to deal with my husband's behaviour moments and my husband has had support through his anger management sessions. (Partner T2)*
- *We are supported by staff who work well with families. (Mother U10)*

Some identified that the PwBI received support but that they did not do so directly, their learning was either autodidactic in nature or absent.

- *I've been supported well through good care and treatment for my husband in specialist rehab, but this support is aimed at him (which in turn helps me) - I have not formally been supported to adjust or learn to deal with poor behaviour / aggression / memory adjustment etc etc - I have learned these myself through reading extensively and info on websites plus getting involved with the therapists. (Partner T2)*
- *Rebuilding my life - My life (and my daughter's life) has changed forever too, but there is nothing to help me work out the way forward. (Partner T2)*

Whilst the nature of the difficulties faced was very varied, from those who require round the clock nursing or behavioural interventions to those who had far less obvious or even very subtle difficulties, the impact is felt across time and by more than the PwBI themselves. The respondents identified more regularly than not that the response they received from the wider community and from services was either inadequate or actively damaging. The invisibility of most post ABI difficulties and the impact loss of insight plays in this, alongside lack of knowledge by services, conflates to exacerbate the negative aspects of the respondents' experience.

Q 33 Knowing what you know now, what would you do differently if you could go back to the time when your relative/friend was first injured?

Seven individuals noted that they would change nothing, either as they were satisfied that they did all that they could or that they did all that was possible for them to do at the time.

- *Not a lot - fought hard at the time and spoke up - lucky to have strong character in the first place...Never give up no matter how bleak things seem....* (Mother A10)
- *Feel confident now that the difficult decisions we had to make for my son were indeed beneficial in his rehabilitation.* (Mother T2)

The majority of the answers to this question related to respondents stating that they would have become more involved at the earlier stages, asking more questions, gaining more information, advocating for the use of specialist (not generalist) services (and sooner) and to have been more assertive in relation to pushing for services for themselves and the PwBI. These responses related to inpatient, discharge and community settings although discharge to the community is specifically mentioned most frequently.

This question, of all the questions that provided open ended answer opportunities in the online survey, appears to have provided the greatest degree of uniformity of theme in the responses, that of the need to learn to be able to effectively advocate on behalf of PwBI by recommending assertive and informed involvement and an insistence on appropriate specialist services to be provided in a timely fashion.

- *I would ask more about prognosis and long-term changes. I would not have brought him home from rehab as soon as I did (I didn't understand his problems).* (Partner T2)

- *Rehab as soon as possibly is so important, question everything, medical professionals do not always make the right decisions, so question their rationale once questioned they then often rethink and change their minds. (Mother T6)*
- *Contact a brain injury case manager early on to ensure he received the correct treatment, and the family were supported. His brother and sister are still struggling to come to terms with it, and my 31 year old marriage has ended. (Mother A6)*

The need for family/friends to involve themselves and advocate on behalf of the PwBI and themselves was also noted in relation to litigation as well as to clinical decision-making.

- *I would insist - or at least try to insist - that no settlement for compensation took place until several years post accident, and I would also insist on being present at all meetings with solicitors. I would also insist that compensation was put into a Special Needs Trust - nobody told us that such a thing existed... (Mother A10)*
- *Not trust social services. (Uncle A2)*
- *I would arrange education for our family, close friends and develop a process to ensure that we all helped and not hindered the recovery process. I would also arrange counselling services for the family in readiness for his return home so that the transition was smooth and less fraught...instead of it impacting so negatively on everyone. (Partner T2)*

Other respondents noted, in some cases flippantly, that the knowledge gained would have made them change their approach significantly or that they could not have done anything differently.

- *I'd have ran a mile. (Partner A2)*
- *I think I'd have given all of his friends more info, many of them have drifted away. (Father A2)*

- *Pray for him to die rather than pray for him to live and possibly to die myself to.*
(Mother U10)

The responses to this question were amongst the first to highlight that the lack of respondent knowledge of the condition affected their decision making and actions at a point in time closer to injury. At this juncture respondents were unaware of the paucity of provision and, perhaps more importantly, the lack of knowledge of the condition by services and professionals. It is at this stage that the unavoidability of the relative's future involvement commences.

Q34: Please use the space below to provide more information regarding the changes and difficulties that you and your relative/friend face. What would you suggest professionals need to do to improve the services provided?

A number of respondents used this last open-ended question as an opportunity to provide a description of the difficulties that they and their PwBI faced, describe their poor experience of services to date and to describe their fears for the future. I have allowed here for more and longer quotes as this provides an opportunity to encapsulate the breadth of the relatives' experience and its meaning for both them and the injured party as well as to demonstrate the positive suggestions for change that were provided. Respondents were able to reflect well on what worked and what did not.

- *My partner was very polite and thoughtful. He would not have upset people on purpose but now he doesn't seem to care which is very upsetting. Community OT has been found lacking. Making promises and not fulfilling them. People need to understand that my partner is relatively young and needs maximum interventions.* (Partner U2)
- *Many people perceive those who have a head injury as people who go into a coma, wake up, and life goes on more or less as normal. When we say we have a son in a rehab unit for brain-injured we get typical questions like "does he know you?" He can do physics questions from a physics paper but he can't*

function on a day to day basis, is inappropriate, invades personal space, is impulsive, needs constant prompting, needs a screen in the car to separate him from the driver in order to move around. (Mother U10)

- *Our situation now is that my son has managed to spend all his compensation and is living on benefits. He is effectively unemployable due to the problems stemming from the brain injury, and is very dependent on us (his parents) in order to cope with the world. What will happen to him when we are no longer around is something that is hard to contemplate. (Mother A10)*
- *I can only say we were dealt with in an offhand and callous way by most of the staff we had initial contact with and the level of care and concern for him and us was zero. Things like 'Casualty' on TV make us snort with derision as it couldn't be further than our reality. (Sister A10)*

Further themes were linked and included involving family more, in terms of providing accurate information, working together, with a positive attitude to family/family involvement and providing direct services and support. Having a single point of co-ordination, having specialist knowledgeable services that were “joined-up”, continued across to the community and with follow up, long-term follow up if necessary.

- *I think professionals need to listen more to the people involved in looking after someone, rather than working to unrealistic guidelines. (Mother T10)*
- *Professionals could maybe be brutally honest in how life can and will change with any brain injury. In my experience too many years were wasted trying to push my sister into the 'normal' world when she quite clearly couldn't cope, but we didn't know that. (Sister A10)*
- *Explain the injuries the person has had and the long-term consequences of a brain injury. Families think they're failing when they cannot cope. (Child U10)*
- *Respect parents - work with us sensitively and make allowances for our trauma but realising that we still have a voice and can positively contribute to the recovery not just as a parent but as a person with knowledge and in the rehabilitation arena. We don't want to be talked at but - to - as a co- equal. (Mother A10)*

- *Grief needs to be addressed. Difficult when nobody died. Education on all sides. (Mother A10)*
- *Services need to allocate x 1 link person who is specialist in a holistic manner. (Father U2)*
- *It took some 6 years for us to get a brain injury case manager. We went through various people being case manager including a district nurse, community matron, mental health case manager, domiciliary agency manager. None could fulfil the role. Only when brain injury case manager became involved did my son start to get a proper multi disciplinary team approach. (Mother A6)*
- *I was overwhelmed by the amount of extra work researching what was available while trying to cope. Really needed a full time case-worker to manage the research, appointments and paperwork freeing me up to emotionally support wife and daughters. (Partner T2)*
- *Get involved, don't patch up the external visible injuries and then leave them to muddle through for 20+ years. (Partner T10)*
- *Specialist rehab should be provided for very lengthy periods for severe brain-injured people - there is no short cut - this treatment is long and painstaking but there is no other way - occasional services (psychology / OT / Physio etc) are useless. All staff at all stages of neuro treatment should be fully aware of the full range of difficulties people face and should make early adjustments for these (e.g. wall planners, not expecting people to remember things!) I could write a book! (Partner T2)*

The need for more generalist services to be better informed and more aware of brain injury was also a theme as was the attitude of staff.

- *Social Services and GPs need to be much more aware of brain injuries and the effects it has on the person and their families. There should be training for agencies that deal with the aftermath of an acquired brain injury. I feel we didn't get the help we needed because these services didn't understand the effects of what had happened to him. (Sister A6)*

- *The professionals still need educating in the needs of brain injury, especially Social Services they seem to have no understanding. (Mother A10)*
- *There is a staggering amount of ignorance around brain injury amongst health care professionals. I would suggest training programmes are rolled out throughout all allied health care professions during training. I cannot put into words the absolute desperation families find themselves in following such a significant traumatising event. (Mother A6)*

Respondents' descriptions of their experience of the impact of ABI demonstrated how far from their prior existence the injury caused them to travel and how unprepared and unsupported they were with this. The injury has a clear impact upon them and the services/information that they are offered (if any) are regularly wholly inadequate giving rise to extensive difficulties and need for input whilst in the midst of grief and endeavouring to develop an understanding of their losses. Such experiences give the respondents a position of great knowledge upon which to base their views of suggestions for changes to service provision; an genuine insider account of unwelcome and hard learnt wisdom.

Chapter 5: The Interviews: Findings and Analysis

5.1: Anonymity and coding

Anonymity of participants and their family members has been protected by replacing any names mentioned with pseudonyms. Named professionals are referred to solely by their job titles and named towns/cities etc have been replaced with “the city” or “the town”; named services or hospitals are simply referred to as “hospital” or “rehabilitation unit” etc.

To enable individual participants’ comments to be tracked through this chapter a key has been created consisting of the relationship with the injured person and a unique number code. Where appropriate, sub-themes have been identified within the main theme.

No.	Relationship to injured party	Living arrangements	Years since injury	"Name" of person with ABI	Gender of injured party	Age of injured party	Cause of injury	Code
1	Partner	Live together	6 – 10	Robert	Male	36 – 50	RTA (Passenger)	Partner 01
2	Sister	On own	10+	Lisa	Female	36 – 50	SAH	Sister 02
3	Mother	Live together	6 – 10	Jake	Male	11 – 18	RTA (Pedestrian)	Mother 03
4	Partner	In Unit	2 – 5	Simon	Male	51 – 65	Stroke	Partner 04
5	Uncle	On own	2 – 5	Pierre	Male	26 – 35	RTA (Bike/M'bike)	Uncle 05
6	Mother	On own	10+	John	Male	36 – 50	RTA (Driver)	Mother 06
7	Partner	Live together	2 – 5	Andy	Male	51 – 65	RTA (Driver)	Partner 07
8	Partner	Live together	2 – 5	N/A	Male	26 – 35	Assault	Partner 08
9	Partner	Live together	2 - 5	Terry	Male	51 – 65	Stroke/SAH	Partner 09
10	Partner	Live together	2 – 5	Brian	Male	51 – 65	Stroke/Trauma?	Partner 10
11	Mother	On own	10+	Owen	Male	26 – 35	RTA (Passenger)	Mother 11
12	Mother	On own	10+	Peter	Male	36 – 50	RTA (Driver)	Mother 12
13	Mother	In Unit	10+	Graham	Male	36 – 50	RTA (Bike/M'bike)	Mother 13
14	Mother	In Unit	10+	Sean	Male	36 – 50	Anoxia	Mother 14
15	Partner	In Unit	2 – 5	N/A	Male	36 – 50	RTA (Driver)	Partner 15
16	Mother	On own	6 – 10	David	Male	19 – 25	RTA (Passenger)	Mother 16

Table 18: Anonymised information regarding participants and individual codes to aid identity

SAH – Sub-Arachnoid Haemorrhage. RTA – Road Traffic Accident

5.2: The Themes

Six themes were inductively developed from the transcribed interview data via the method described in chapter 3. The themes are linked, developing a thread from point of accident/injury to its impact on the person with the brain injury, to the impact this has upon the non-brain injured, the impact this has in relation to enforced taking of responsibility by the non-injured and the interface with services, poor experiences and good ones.

One further and overarching theme was interpreted as a consequence of stepping back from the data and themes and reviewing the interviews more broadly.

The themes were:

1. *The context:* The nature of severe brain injury impacts upon relatives and does so within a pre-accident context that affects how it is experienced. This theme sets the scene for what follows and is seen via the lens of the relative who reports their prior lack of knowledge and the immediate impact of severe injury.
2. *The all-encompassing challenge:* The impact of severe ABI is complex, far-reaching and extremely challenging. In this theme relatives report upon changes to their loved ones, the severity and complexity of this and how this affects all aspects of their lives.
3. *Family loss and grief:* Relatives live with their own complex trauma, losses and grief. Relatives described clearly their changed internal state, how changes to another person impact directly upon their identity and emotional well-being.
4. *The unavoidable burden:* Relatives' burden of care is unavoidable and difficulties are not limited solely to issues related to the brain injury. As a consequence of the prior three themes, it is the non-injured relative who

engages with the outside world on behalf of the injured party, this was not described as a choice by relatives.

At this point the themes split from the more linear ones developed above. Experience of services was reported in a polarised style, services/professionals were experienced as poor/very poor or as excellent. I separated the resultant themes along these lines and have chosen to present them as such to provide a greater degree of opportunity to clarify differences between what is reported as helpful what is not.

5. *The poor experience of support:* Difficulties experienced are exacerbated by formal and informal responses provided.
6. *Positive support and change:* Positive change can occur and this can be supported by formal and informal structures; the relative plays a part in knowing how this can be achieved.

Overarching Theme:

The curator of narrative: Overarching everything, the relative is key to holding the narrative threads of the past, the present and the future. They are alone in being able to perform this task.

5.3.1: Theme 1: The Context

The nature of severe brain injury impacts upon relatives and does so within a pre-accident context that affects how it is experienced.

Participants experience a significant trauma of their own as a consequence of their emotional/familial relationship with the injured party. Pre-injury experience, circumstances, responsibilities, roles, coping strategies and knowledge affect how the injury impacts upon the participant.

Hearing about the accident and the early days

Every participant recounted their story of the brain injury, how it occurred and how they were informed. Invariably this was traumatic and unexpected:

I basically got a phone call saying, "We're taking her in for surgery, it'll be at least seven hours. She might survive, she might not"... He said, "She could come out paralysed, blind," He said, she had a 50/50% of survival and all that. So he said, "just make your way over here and tell your parents to come,"
(Sister 02)

For those who witnessed the accident or the immediate aftermath there was an added dimension of not being able to help loved ones at the time, in this instance at the roadside. The young man in question was unconscious, his mother was however upset by the notion that her son was not aware that she was present:

I remember a policeman kind of flagging us down and saying, "Come on, come through here," and her saying, "It's his mum." [...] When they put him on the stretcher, they seemed to then kind of run to the ambulance, shut one of the doors and – where I'm thinking, oh my - you know, and I remember calling out his name and heading towards the – being stopped by a police officer saying, you know, "The ambulance is waiting for me to escort it, or whatever, come in the car with me." Obviously being kind and what have you. I said, "But he doesn't know I'm here and he needs to know that..." (Mother 03)

Reports of the initial admitting hospital were similarly described as times when participants first saw the injured party and started a process that would be on-going and outside of prior experience.

During this period a number of family members were given very negative prognoses and were confronted with the decision to remove life-maintaining treatment:

They got him to hospital and he was ventilated and he was put into the neurosurgical unit and they scanned him at some point and they said he had a massive brain injury, a major brain injury with tears and a massive bleed, everything, and he wouldn't go through the night. They didn't think there was anything they could do. But they ventilated him and they put all stuff, you know, the tubes and things in him that they do and we just sat by the bedside. Anyway it was the Neurosurgeon sort of came in the morning and he said, "Well, we've got him through the night," he said, "that's a good sign". He said, "But looking at the brain injury" he said "his brain is swelling and there's nothing we can do, I'm sorry to tell you that he will die". Anyway at some point they said his brain was swelling to such a proportion that they would be just as well to switch off the machinery and let him go and take organs and that sort of thing and I said, "No, no, you're not doing that, it's not time yet, you're not doing that."

(Mother 06)

In this instance the relative's insistence to maintain treatment has been vindicated by the fact her son lived and has done so in the community for over fifteen years since it was suggested that the ventilator was switched off and his life ended accordingly. As is noted in the literature, issues with prognostication and accuracy of diagnosis, particularly in the light of a requirement to find healthy organs to harvest for transplant, leads to questions about the ethics of treatment at this juncture. Family are usually wholly outside of their usual experience and are in emotional turmoil (Fins, 2015a, 2012). This experience stays with the participant, is frequently traumatic, is

remembered and is the start of the process of what is, unbeknownst at the time, a likely lifetime experience, one that can start in conflict and confusion.

Several participants work in the field of health and social care and had therefore more understanding of the potential meaning of the injury sustained as well as increased familiarity with hospitals and their staff. This affected their initial understanding of events, pre-existing knowledge not always standing to reassure the participant, sometimes the reverse being true:

The doctor came and said, "Now, it's going to be hour by hour if he survives. He's got an occipital fracture." I said, "That's great, you can do a drain and get the blood clot out." They said, "No a condyle." I thought, "Oh, fuck." That's it, isn't it really?*

(Mother 16)

**An occipital condyle fracture is associated with very poor (fatal) outcomes as the cervical spine is left very unstable, slight movement can lead to instant death (Alcelik et al., 2006). This was first described in the literature following the surprising sudden death of a discharged patient on simply turning his head to say goodbye to medical staff (Bell, 1817).*

The context the ABI occurred in

The participant's and the injured party's pre-accident life, roles and expectations provided the context for the losses that were to be experienced:

Andy ran a health food business in the city; had 15 staff working for him, it was a busy, busy business. I was teaching, teaching four days a week and one day a week I would go into the shop and do accounts things really. And I was teaching in the village school up here, permanent job, lovely, ideal, nice being part of a village. At the time as well going through this just before that we'd gone through IVF after five however long times of going through it we were going through that with our final shot and that was in the May. (Partner 07)

In this instance, nearly five years post-accident, the business, the teaching position, the opportunity for IVF (and if successful, parenting) and the sense of being part of village life are all roles that have gone as a direct consequence of the ABI. Strain, disappointment, and isolation are identified as areas in which carer burden is considered high as a consequence of the role of relative of a person with an ABI, the losses are significant and affect a range of roles and future opportunities (Manskow et al., 2015).

Other individuals experienced ABI during periods of upheaval or difficulty. Whilst such difficulties or challenges can be experienced outside of the context of ABI by others, the role ABI plays in the participants' experience is to add a further level of complexity that they need understand and/or respond to:

And then he moved to the city with his partner and they were buying a house, and that's when all things went wrong with his relationship again. And... that's when the car accident happened. The girlfriend went away – there was a baby; Peter thought it was his baby but it wasn't.

(Mother 12)

Participants also noted the variation in other relatives' ability to cope with the consequences of the injury. This formed part of the participant's experience and was an added dimension to cope with or be supported by, the context of the injury is therefore multifarious and broad and affects and shapes this experience:

Pierre's mum, as I said, she finds difficulty in handling stressful situations, basically she breaks down and gets very aggressive and angry and she's not rational, she's not like that all the time but it gets to that very quickly.

(Uncle 05)

The ABI was therefore set into a pre-existing context of roles, difficulties and responsibilities for both the injured party and the participant relative. These

contextual details formed and shaped views, resources and coping for the post-injury life.

5.3.2: Theme 2: The All-Encompassing Challenge

The impact of severe ABI is complex, far-reaching and extremely challenging.

The very wide range of difficulties reported as a consequence of the injury, both in terms of impairments and, more regularly, their functional impact, were noted by all participants to have caused very significant changes to their relative's lives and likely future options. Many of the changes brought by the brain injury make supporting the relative difficult. Behaviour in public, lack of ability to have concern for others and loss of insight in particular are noted to be challenging and the situation is one where no clear resolution can be perceived.

The participants reported different issues that they and their brain-injured relative had to contend with, including aspects of physical care, prompting, behavioural management, planning, dealing with services and supporting the injured party to either maintain their place in the community or, for those who resided in specialist units, to maintain contact with the wider community. Participants actively supported their injured relative's engagement and participation in day to day life.

Consequences of the ABI on the affected individual

Outcome from ABI is noted in the literature to be incredibly varied (Newby et al., 2013) and participant reports highlight this in respect of those who are very physically and cognitively impaired, requiring round the clock care:

He is right-side affected, so he will never walk, he will always be wheel-chair bound, he can talk but it tends to be a whisper, he doesn't initiate any conversation, so if we were to sit here, he wouldn't speak. If you ask him how he is, he will say 'I am fine', and he might then say 'How are you?' and then engage in conversation. The easiest way to explain it, which they did at assessment, if they were to put Simon in the corner of a room, facing the corner

of the room, he would stay there all day. He wouldn't be happy, if you asked him if he was happy, but he can't ... he hasn't got the cognition or the initiation to say he is hungry, thirsty. He is doubly-incontinent, obviously gets very tired, just part of the brain injury. Yes that is kind of how he is.

(Partner 04)

To those who, whilst able to undertake all activity independently, cannot do so as a consequence of a specific lack of ability to initiate activity:

You have to prompt him to give him his medication, you have to prompt him to have a shower, you have to prompt him to use shower gel, because he will just stand under the shower.

(Partner 01)

Others are similarly able to physically function without assistance, but do not because of executive impairment:

He wouldn't function without me. He'd like to think he would function without me. He can't. He won't motivate himself to eat; I have to make sure there is food there all the time and he loves it when he does eat, but unless I say, "Do you want something to eat?" "No, I'm not hungry." When I was working in the shop I would ring him ten times a day, he doesn't pick the phone up, only to me, he would let it ring and ring and ring and go to answerphone. Me, I'll say, "Andy, can you pick the phone up? It's me! Can you pick the phone up? Can you eat? Have you eaten? So if I wasn't in the equation I don't think he would eat properly because every day I'll say, "Right, for tea we'll have this, this and this," I have to be specific because if you give him a question, give him two things, "I don't want anything," because I've given him a choice. The choice is there and he can't cope with choice. So I've gotten now to the stage where I'll say, "We'll have this." I don't care.

(Partner 07)

In the three examples above the person with ABI has differing underpinning reasons for their lack of ability to function fully independently. Lack of ability to initiate activity (in the case of using the shower gel) or lack of ability to make a choice (between two meal options) are invisible deficits (Rutherford and Corrigan, 2009). In all three cases it is necessary for another party to proactively prompt functional tasks as varied as conversation, medication and eating. All three individuals are not simply “forgetting” to undertake an activity but require specific support to do so. Providing such support through removal of choice may run contrary to early versions of a social model of disability (Finkelstein, 1993, Oliver, 1993) but reflects the underlying difficulties ABI can bring with regards the possibility of making a choice; in these examples providing choice prevents the necessary activity from occurring, it is the disability. A more nuanced understanding of what promotes inclusion and well-being is required (Terzi, 2004). Responses that do not directly and needlessly confront impairments but instead start from an understanding of them, integrating this knowledge to underpin interventions are required (Clark-Wilson et al., 2014, Giles et al., 2005, Jackson et al., 2014, Jackson and Manchester, 2001). This does not sit easily with social work or other models that assume that expertise is sited with the person with the disability (Noorani, 2013, Beresford and Carr, 2012) but may be reflective of the reality of family management of social care services by family (Brennan et al., 2016) although such research is invariably related to those with profound physical and cognitive impairment. This research identifies that such difficulties, the need to negotiate around impairments, takes place with those with executive difficulties.

Behaviour that challenges

The behaviour of the brain-injured party, either active behaviours such as impulsivity, aggression and disinhibition or passive behaviours such as lack of initiation or forward planning, can lead to difficulties for participants who were responsible for managing the injured party and mediating their dealings with the wider world, including that of managing and intervening with behaviour that may otherwise cause conflict or difficulty:

I mean we were in the hospital once, and sat there, and there was a lady sat there, minding her own business, I did feel sorry for her, and he went into a stare and this woman was getting really you know ... really embarrassed and I thought oh God I am going to have to explain so I just stood in front of him, so he was literally staring at my back, so she didn't feel uncomfortable, and then I didn't have to explain it. So you have to kind of watch him.

(Partner 01)

Participants identified behaviours that may be considered extreme, potentially dangerous and/or illegal and outside of previous experience or knowledge, requiring significant skill, tolerance, understanding or patience to manage, contain or cope with:

The mental health issues he was having were not exactly good; a lot of them are sex-based, so there was a little bit of sexually inappropriate behaviour with people he knew, family members even.

(Uncle 05)

John started with the anger. Enormous amounts of anger. To the point that he would, we lived in rented accommodation at that time and he would punch the doors and the walls. He actually put holes in some of the walls so I just put a picture over them and thought sort that out another time. Absolute raging. Terrible tempers, and you know, my son's six foot four.

(Mother 06)

Issues with Insight

Loss of insight into ABI-related difficulties is noted to be common within the literature (Prigatano, 2005) with individuals least likely to have awareness of their behavioural difficulties (Hart et al., 2009). Participants who experience this are therefore not engaged in a fully joint and shared endeavour with the injured party, the responsibility and burden for understanding and responding to the condition falls to the relative:

But he has still has no insight at all into his own mental difficulties,..... he has no insight at all to his own condition.

(Mother 11)

Insight and self-awareness are, in themselves, nuanced constructs. Participants experienced the somewhat confusing nature of their injured relative being able to state their condition, seemingly showing understanding in doing so, but not to be able to connect this knowledge with the action that is required as a consequence:

I think the hardest thing as well, is his lack of insight means that he actually doesn't really, despite the fact that he can articulate those deficiencies really well, he makes no connection between his inability to do something and the fact that that's – you know. He'll say "Yeah, I've got issues with the planning and organising and being able to make a plan", he'll tell his friends that and I'll go "Great, so let's get some goals down for the next few months" because I try to keep him focussed, and "Yeah, yeah, I know what I'm doing", so, a blank piece of paper, and I get upset because of what he achieved and who he was and how clever and brilliant he was to someone sat with a blank piece of paper not being able to make the connection between – he doesn't know...

(Partner 09)

As described in the literature, participants were able to identify this disconnection between saying and doing, where a person with an ABI has an intellectual awareness of deficits and, in the above example, may even be able to identify processes to ameliorate this but not be able to enact it in real-life settings and in-situ (Bach and David, 2006, Crosson et al., 1989). Such behaviour is counter-intuitive and participants learnt strategies, such as removing choice, over time. Lack of insight into their condition and the impact of behaviour (active or passive) was noted by participants to exacerbate the difficulties they experienced when supporting the injured party. In this instance the person with the ABI cannot link their impairment with the need to rely upon services other than their partner. The repetitive and ongoing nature of the difficulty, seemingly without end, adds to the participant's perceived burden:

I've been trying to convince him, for example, that we need a support worker and I've even done the "It's not a support worker; it's like a personal assistant", trying to – but of course he can't – "Why? I don't understand why I need that." So now I'm positioning it as "No, you don't need it; I need it". So it's my support and it's someone that you can ask the same question 50 times to and not ask me.

(Partner 09)

The Impact of the ABI in the future

Concerns about the future were regularly reported, more often but not exclusively by parent participants. The future is unclear and concerning with the impact of the ABI developing over time as participants became more aware of the nature of the injury in different contexts and how this impacts upon the present and the future. This growing awareness, formed by increased experience of life post-ABI, is further complicated by the sometimes subtle and invisible nature of the changes. The impact may be considered cumulative, the complete picture is not available at the outset. Participants did not have full control over the environment of the injured party and their interactions with others meant a loss of control. Participants made choices and decisions on behalf of the injured party (Knox et al., 2015):

I was trying to put the things in place in a haphazard way maybe, put things in place that would help him maybe in the future because I didn't know what was going to happen. By that time he'd met up with another woman and she'd sort of moved in, and she was alcoholic.

(Mother 12)

The all consuming nature of this in some instances prevented people from considering more than the immediate future and/or situation and gave little possibility for clarity or longer-term planning. Giving thought to anything but the immediate provoked tears, the future is simply overwhelming:

I don't really look ahead, I take each day. I honestly don't know. Life isn't easy, I'll admit life isn't easy, life is challenging... sorry, I get upset. I don't know, I really don't know.

(Partner 07)

This process is anxiety-provoking for the participant; in this example more than 20 years post injury it also appears unending:

I worry about him constantly. I worry about his future constantly.

(Mother 14)

In the case of a partner who was expecting her husband to return to the family home after more than two years in hospital and residential rehabilitation settings, the desire to not be classed as carer, to re-assert the role of wife, was clear. However, the absence of clarity regarding whether adequate paid support would be forthcoming (and the injured party's reaction to returning home with support) clouded this. There is also a contradictory sense of being feeling duty-bound to be willing to do anything whilst not wanting to subsume identity to one of 'carer':

I don't know how it'll pan out till he gets home, really. It's all well and good, isn't it, going, "Oh, I'm going to go to work, I'm going to..." I don't know. I don't know. I think there's a lot up in the air with carer issues. I really don't want to be classed as his carer. I want to be his partner, not his carer. I'll do anything, obviously, you know, but I don't want that – I don't want me to be included in their equation. Does that make sense?

(Partner 15)

Some participants reported having little or no support and accordingly having no reassurance for an uncertain future, in particular when, as may be expected, parents pre-deceased their children with an ABI. Such notions, the need to plan for a time post-mortem for the participants, is one that is a component of the participant's experience but not one that is easy to conceptualise or manage:

And again that's come to me more where I- I was asked that question, like if I – I'm thinking if I'm not here for a day or..... where I thought, oh wow, I've no idea. Oh my gosh, who would – what would happen? And I'm now kind of thinking, you know, I've got to set that in place. That's a must. That's a – because there's no one who I would – I mean, I've no idea.

(Mother 03)

Whilst participants identified the need to forward plan to create support structures, in particular for a time after they had died, their ability to do so was limited by factors such as availability of services, of other willing and able relatives and by difficulties conceptualising how the injured party could be supported (Knox et al., 2016).

5.3.3: Theme 3: Family Loss and Grief

Relatives live with their own complex trauma, losses and grief.

All participants noted the losses that the brain injury brought and the emotional impact that this had upon them and others in their social milieu. The nature of the grief caused by the injury was identified as complex and one that relatives felt generally very unsupported with, in particular if the injured party had made an ostensibly “good” recovery in terms of physical abilities. The grief was identified as being endless, caused by changes to the individual by the brain injury, by role change, by loss of previously held expectations and assumptions, and the necessity for the participant to take responsibility. Participants were able to describe understanding their grief, recognising losses, but noted that they felt alone with it. It caused some to question the value of the life of the injured party.

Participant loss of identity

Participants' own sense of self-identity, roles and expectations were clearly impacted upon by the injury to their relative. Participants identified past and present losses but also noted 'future' losses that had yet to be experienced but felt inevitable owing to their circumstances. Adjustment to loss was therefore complicated, on-going and

uncertain, sometimes wholly unsupported by professionals and the wider community or, in some instances, exacerbated by formal and informal input.

The invisible nature of the changes to the person with an ABI coupled with a lack of understanding of the condition by the wider public reinforces the difficulties felt by participants. Rather than being supportive, this mismatch between the participant's reality and the ignorance of less involved parties serves to isolate the brain-injured family further (Linden and Boylan, 2010) and is frustrating (Brown et al., 2013).

So yeah, that's what's really difficult. And I know sometimes when people say "Oh well, at least you didn't lose him," I think "Oh god, you're so naïve", of course I lost him. I lost him, I lost my identity – he didn't just lose his – yet no one thinks about that, it's just... And of course you can sometimes see Terry in a thirty minute period and he's great and everyone will be like "Oh god" and then of course you feel like you're whinging because everybody else is like "Well, I don't understand what she means; he's fine". But then you shut the door.
(Partner 09)

The injury directly affects one person; however the outcome is noted to have a significant impact upon the participant too, changing their life and their opportunities, forcing increased responsibility (Knox et al., 2015).

And that's one of the things I've been really, really angry about, that it's not just been his life that's been changed, my life as I wanted it has been changed. Things I've wanted to do have been restricted, and I've been angry about that. Very, very angry.
(Mother 06)

Invisibility of ABI changes and ambiguity

The complexity of reconfiguring relationships was identified, made worse by the fact that the injured party was often physically unchanged.

The person that you used to share everything with has gone and you're left with someone that vaguely resembles the man that I once fell in love with but isn't him

(Partner 09)

In this sense participants' demonstrated ambiguous loss (Boss and Carnes, 2012), complex grief for a "non-bereavement" that affected every aspect of their lives and identity, interrupting the previously held sense of self-narrative, disrupting their assumptive world and generating ambivalent emotional responses. However this sits outside of normal opportunities for mourning rituals usually associated with death.

I think you never properly grieve for what you've lost because you can't, because you haven't but you have.

(Partner 09)

Complicated grief

Grief is complicated by the loss of the pre-accident person, the loss that this causes to the participant and the loss that these changes cause to their pre-existing relationship (Godwin et al., 2014). One participant invented her own mourning ritual, an explicit acknowledgement of the 'social death' of her son. Whilst this was perceived as helpful, it did not provide closure, the pre-accident loved child is wanted and not the violent imposter that stands in their place.

I've put flowers on the crash site, I did do that. And I had counselling as well, I had counselling which helped me, and I had loss counselling because they think that's what's not recognised is that the person that you have actually dies. And then you've got to look after this stranger and learn to love this stranger and you don't want this stranger, you don't want to love this stranger, you want the old one back.

(Mother 06)

Participants describe the paradox of the 'living being dead' in this sense and the ambivalence it creates for them, wanting something impossible whilst knowing it is impossible (Boss, 2010).

The nature of this grief is lasting, perhaps unending, and the majority of participants wept when considering the losses that had taken place.

Sorry, it's all these memories.

(Mother 12)

Grief exacerbated by services/lack of services

Simultaneously participants encountered the unavoidable burden created by the need to become involved with a combination of outside agencies that variously included health, social and rehabilitative services, as well as those associated with civil litigation, education, police, the courts, prison and others. The structures, practices, eligibility criteria and boundaries of services were regularly noted to not "fit" the needs of brain-injured people.

You are probably aware of the DST (Decision Support Tool)? I mean the first two categories are behaviour and cognition. Now behaviour can be verbally, verbal behaviour, or can be aggressive, but it can also be passive. Simon has high passive behaviour, so he is at high risk to himself, high risk of being exploited, and in the DST, on the form it says that passivity must be taken into consideration, in the same way as verbal and aggressive, but it wasn't, and even in both those assessments, my sister and I were fighting, and so were the MDT (Multi-Disciplinary Team), fighting.

(Partner 04)

Individuals living with on-going and complicated grief found themselves contending with services that are structured in such a way as to make intervention impossible. Assessment tools and protocols failing to take account of the reality of ABI and 'rules' about service provision being arbitrary, perverse and illogical.

Apparently he can't have physio, he can't have psychology (in the community), which are the things that he needs. But you can't have physio unless you've got learning difficulties in the community.

(Partner 15)

Participants needed to advocate over long periods of time and at the highest possible levels to attempt to achieve access to services. Doing so for decades with little hope of change but being unprepared to give up.

And I write letters to everybody. Keep fighting. Might not achieve anything but they'll all know my name by the time I've finished. The last advice I got was- got a letter from the health committee which- our health minister who you can only admire for his ignorance. They've no idea what you're dealing with here.

(Mother 14)

People with an ABI were noted to not "fit" service provision, to be outside of structures and common understanding. Advocacy was undertaken in hope, but also in the knowledge that those in positions of authority and power are ignorant of the condition.

I informed the court about his brain injury thinking it would help and then when he went for sentencing they mentioned his brain injury and the magistrate put her hand up and she said, "We're not here to hear these excuses".

(Mother 06)

Losses that cannot be understood by others

Participants noted that the injury impacted upon them and other family members emotionally but that it was different to, and potentially more complicated than, a bereavement, and outside the experience of other people, professional or otherwise. As brain-injured people do not fit service provision, nor do their grieving relatives.

One of the mums at school, she runs like a bereavement group for children, so I am trying to see whether that might be useful for Evie, because you see in a way, it is a bereavement, and it is really ... but again we don't fit that, because we have got no closure.

(Partner 04)

Informal support structures to help cope with family grief were noted to vary in quality and usefulness. Acknowledgement of this leads to the participants no longer attempting to receive support, recognising that theirs is a burden that others cannot understand and so cannot help.

Friends – to be honest I don't really talk to my friends much about it, just because I do struggle – I don't like to go on about it too much because I feel – first of all I feel as though it's probably boring to them now because it's been like years.

(Partner 08)

The unending nature of the loss leads to some no longer seeking emotional support, leaving the participant without either formal or informal support to help manage and adjust to their on-going grief.

I have stopped ... rightly or wrongly, I have stopped offloading to friends and family.

(Partner 04)

Even when support is agreed and services are put in place, simplistic notions that the participant can now “get on with life” are rejected as lacking understanding of the actual impact of the injury, the absence of clarity that such an ambiguous loss brings. Families are left dislocated from their prior experience and expectations. Much of their world remains the same but it is unfamiliar.

Up until now, I have been fighting for Simon's assessment, and then a lot of friends and neighbours (once I got that result), 'right, now you can move on, you can start getting work, or going and finding a hobby'. But I am ... as I say, I am very lost at the minute, I kind of don't know where I am.

(Partner 04)

Continuous bereavement

Even for those who are able to live together post ABI, the loss and the sense of a loved one being absent remain, this endures despite their actual presence. It takes time for the participant to realise that they are grieving for the absence of the person who is in fact present but simultaneously is not.

I really, really miss him; I miss him a lot.

(Partner 09)

Participants described a sense of isolation and, even when well supported (professionally and/or personally), some relatives described being alone with these changes. The nature of brain injury is such as to make the relative feel alone even if they live with the brain-injured party and for them to lose a sense of themselves and of how their future may be created, incorporating their new identity.

There's no goodbyes, no, there's not, "Oh, that's happened, now I can't have that person anymore, I've got to get over it," I look at that person and wonder where is he? Is he in there somewhere? And now and again I get a glimpse and that's very upsetting when you get a glimpse.

(Mother 06)

Again it would seem counter-intuitive but the notion of seeing "the real person", catching sight of pre-accident personality characteristics or behaviour, can sustain grief as the reminder of 'what was' is juxtaposed with 'what is'. Explaining this to others is avoided and so burden is increased and prolonged by the highly personal and private nature of the grief.

The long-term or lifetime nature of the ambiguous loss as well as the absence of clarity for the future was also commented upon. Participants with many years experience of brain injury identified this absence of notions of “closure” and the emotional strain that this creates for them. Grief for what would have occurred but for the ABI leads to anger and sadness, losses that cannot be calculated and are not recognised as losses by those not directly affected.

How do you grieve for somebody who's still alive, yeah? But you grieve for relationships that are gone and in a way I feel now sometimes angry and I can feel the grief; that I grieve for what might have been. Perhaps my expectations as a parent, what I was hoping for, for Peter, didn't work out that way.
(Mother 12)

Participants used terms such as “continuous bereavement” being without “closure”, seeing theirs as an on-going grief, one that could not be resolved.

I absolutely can see why marriages fail because it's a different person, it's a completely different person. The difficulty I think for us, and this is I think the sorest bit of it, is that it's a bereavement without any closure and you are left with all the belongings of the past and they are still there because this person has some association with them but they don't belong in the same way. There is a bereavement and there is no closure.
(Mother 13)

Steps towards adjustment and adaptation to this unwelcome grief state are fraught with risks of “seeing” the pre-injury person if they act in a manner that reminds the relative of how they were pre-injury, this can push them back into grief.

It's the dipping in and out because there are times when you think everything is fine, it's grand, coping great, and then, as I say, it just comes up and bites you and suddenly you are very vulnerable again. (Mother 13)

Participants' insightful descriptions of their grief are echoed within the family survivor literature (Giffords et al., 2011, Maxwell, 2009) where grief and hope intertwine, undermining simplistic notions of "linear" grief theories (Wambach, 1986, Kübler Ross et al., 1972).

Having worked in the field of ABI for many years and across many settings I was familiar with the heterogeneous, complex and challenging circumstances individuals find themselves in following injury to a relative. That family loss and grief was a theme was not a surprise to me, albeit the specific story told was always wholly unique and frequently very harrowing. Two nodes that formed this theme in particular however stood out as being ones that, in my professional role, I cannot recall family discussing with me so openly. These were "Not telling others" (reported by 12 participants) and "Better off dead" (reported by 7 participants). I was somewhat taken aback by both the fact that these sub-themes developed but also my lack of prior direct experience of them in practice. Participants reported that they give up seeking support from others as the wider community fails to understand the consequences of the injury and so they no longer explain their situation. Secondly I was witness during the interviews to often tearful admissions as a relative questioned whether survival post-injury had in fact been the best outcome.

Decisions to not seek help

What may be intended constructively and supportive is received as a lack of understanding. Participants do not go into detail and hence an intended positive comment is not received as such by the participant.

I think that's what makes it quite isolating is because of this picture that's been created that's where when people say "God, Terry's doing well isn't he?" you say "Yeah, absolutely; everything's great" because it's too tiresome to – you sound like you're complaining.

(Partner 09)

Help-seeking behaviours are discouraged by the responses participants receive. The complexity of the condition and of the grief process it generates is misunderstood to a degree that trying to explain it can back-fire.

So you don't talk about it, you just get on with it. You think, well I'm not talking about this. They heap on you more pain because they make you feel inadequate or stupid because they don't understand and they don't want to.

(Mother 16)

Family? Oh I don't talk to, I just don't talk to them anymore about it. I don't talk to them anymore about it. They just, they can't take it on board.

(Mother 11)

The burden of coping with the injured party's post-ABI needs and with the participant's own grief is therefore concentrated, the complexity of the nature of brain injury being such that it is felt others cannot understand. This exacerbates the difficulties experienced. Far from being supportive, comments from those lacking insight into the participants position are perceived as actively damaging.

Everybody says to you that you are so lucky that he is still alive, he can walk, and you think, you have got no idea. No idea at all. You don't want to talk about it to people because they can't hack it anyway, can they?

(Mother 16)

They don't get it, and they can't help and they don't want to help. And if you tell them, they think you're giving them some responsibility, you're actually not. It's your responsibility, you just need to share it with somebody.

(Mother 06)

An absence of support-seeking behaviour amongst participants would appear to have been informed and reinforced by negative experience. The support sought would, in

the above example, not be of seeking solutions or even a reduction of burden but simply that over being heard and of sharing.

Questioning the value of the life lived

The interviews were lengthy and the subject matter regularly touched upon very personal and usually private matters of love and relationships. Both of the individuals who played an essential role in saving the lives of their injured relatives questioned the value of this and whether this was the best outcome.

Interviewer: What would've happened if you'd not turned up that day?

Participant: He'd have died. I know that; they told me that. They said he was... yeah, he wouldn't have survived. That crosses my mind too. And yeah, there are things I think sometimes we think and we don't say out loud.

(Partner 09 - Participant instrumental in saving her husband's life)

Participants who had fought for their relatives to live, fought for services and had dedicated themselves to the needs of the injured party, often at great cost to themselves and their well-being, found themselves ambivalent about the outcome.

It is a hard thing to say, and I ... even now wish he hadn't survived. Which is a really bitter thing to say, and I don't want that to go any further. Because I know he wouldn't want to be like this. And because of how painful it is, for me and the kids.

(Partner 04)

The admission of having thoughts of killing one's children, outside of parental severe mental ill-health, is rarely reported in the literature, with one notable exception (Webb, 1998). Webb's paper (and the associated field research reported in Higham et al) identified that the overwhelming and unending pressure felt by family members, most usually in the context of inadequate support and lack of recognition of need, led family members to have thoughts of killing their offspring (Higham et al 1996).

And you know, I've heard of about a story of one woman who drove into a lake with her son and I understand it. 100%. Because it has crossed my mind in the past.

(Mother 14 - Participant was instrumental in saving her son's life)

Such admissions were however within a context of professed love by participants who continued to care and strive for better outcomes for the injured, who continued to have hope and yet simultaneously questioned the value of the life led. An emotional "doublethink", a cognitive dissonance between emotions of love and hope against that of grief and helplessness and, in the quote below, of hate. These emotions co-exist and do so in a context where participants do not find support, formal or informal, easy to obtain.

"Can you remember when we were in the hospital and we said "Dad it doesn't matter how you wake up, just come back to us"?" And I went "Yeah, I remember all of that", and she said "God, how naïve were we?" And I was like "Whoa" that she – and she said "There, I've said it. I've said it out loud, there you go. We were naïve."

(Partner 09 - relaying conversation with her step-daughter regarding their injured husband/father)

The changes that took place to this man were inconceivable at the time of the injury. She and her step-daughter could not conceptualise at that point that there could be a fate worse than death. Only post-injury and with the experience that this brings, can this be reassessed (Kitzinger and Kitzinger, 2013). There is no turning back however.

Reflection leads me to question whether in my professional role I am seen largely as "a fixer". In such a role it is possible that less space is (unintentionally) allowed for the unspoken. As participants stop seeking help from the wider community perhaps they feel unable to voice a loss of hope to those for whom this is a currency? Or perhaps are concerned about expressing their frustration and difficulty to a professional who may be duty bound to act unilaterally upon this? Whereas as a researcher, focussed only

upon the relative, this permitted a higher level of openness, allowed for the taboo of wishing a relative dead to be spoken out loud (Webb, 1998). The role of researcher, solely focussed on the interviewee has been noted to permit openness and the ability to create new narratives that may otherwise be unspoken (Bourne and Robson, 2013).

A great deal of the content of the transcripts fitted my expectations and experience, albeit the focus was solely on the relative, while in my practice I have a dual focus. The ambivalence felt by the participants, the complicated and contradictory emotions, in particular about support seeking and the value of life were, for me, a reflection of the worth of undertaking the research in this manner.

5.3.4: Theme 4: The Unavoidable Burden

Relatives' burden of care is unavoidable and difficulties are not limited solely to issues related to the brain injury.

All participants spoke of the unavoidable nature of their involvement with their injured relative and noted that the difficulties they faced were not limited to issues that solely related to the brain injury. Post-injury negative changes to behaviour, function and independence necessitate the relatives becoming involved in a myriad of different and taxing circumstances, frequently being the injured party's only method of connecting to services or others, including wider family. The fact that participants described their burden of care/support as being unavoidable exacerbates their complex grief and losses as they perceive no alternative but to remain involved despite the impact this has upon their own well-being. Participants note that without their input the brain-injured party's situation would deteriorate and that, usually, there was no other person, professional or otherwise, who could and would take over their responsibilities so they felt duty-bound to continue. Relatives undertake this long-term and seemingly unending role whilst dealing with other issues and difficulties and alongside other responsibilities.

Duty and having no choice

Participants described a lack of choice with regards their involvement.

You cope because you have to. You just keep going and keep going. People say, "How do you do it?" You do it because you have no choice really.
(Mother 11)

However this on-going burden is considered in part a duty, a form of untested, indeed impossible to test, reciprocity.

I couldn't walk away now. Whether I feel differently in five years time, or tomorrow, I don't know. There are lots of times when I want to walk away, but I couldn't, because I know he would do the same for me, I think that is what ... yes, if it was the other way round. What about me? I have got children and I have got to keep going, I haven't got any choice.
(Partner 04)

As with the participants' ambivalence regarding love and hate or life and death there is a contradictory sense of duty, of not walking away, simultaneously expressed with thoughts of leaving and a lack of clarity about how things will change in the future.

You just keep going really. You just do it because you have to do it. I think really. You keep going and you keep going and you keep going, everybody keeps saying, "How do you do it? How do you do it?" I don't think, just do it. You just do it because you have to really. Collapse later. There is nobody else to do it, you do it because you have to. You collapse later, do you know what I mean? (Laughter) You can't collapse. Running on, I lost a lot of weight! (Laughter) You can't collapse, you just have to do it. If I stop now I'll fall apart.
(Mother 11)

Contained within the above quote is the sense of duty, a lack of alternative and the notion that there is no option but to continue, that stopping may be worse. Whilst the

situation can be viewed (by the participant) as impossible to manage and very stressful, they have no perceived freedom to choose and their functioning and well-being is inextricably linked to the injured person and to the role that they play in their life.

Participants take up the fight for the injured, those who cannot fight for themselves, and do this as a consequence of the belief that this is the correct course of action, it is what is needed and so must occur.

The other thing is both of us, I have to say, would have fought to the bitter end for him and I think it's to do with... if it was yourself you would absolutely hate that somebody would walk away from you or not help you to find that. And Graham, where he can't fight for himself, would be a strong enough character and would have wanted you to be there.

(Mother 13)

Concurrent challenges

Participants identified that they have other roles and responsibilities, concurrent with that of supporting the brain-injured person. Some participants became responsible for businesses and employment matters relating to the injured party, others for issues such as care for older parents and lone responsibility for parenting.

My husband was working at the steelworks and that closed down, so there was that dynamic going on as well – it was a wonderful time, it really was. My husband was suffering from depression; and I don't know how we survived.

(Mother 12)

Unfortunately just about eight months after Brian's accident his mum died. She had cancer and so we had to sort of deal with that and Brian found it very difficult speaking to her because he wanted to say things to her but he couldn't communicate with her. So he found that hard as well and things have got worse since Brian's mum died with his dad being on his own and everything.

(Partner 10)

These complex situations are impacted upon by the brain injury, the participant becoming increasingly responsible as either the injured party or others become less so.

Advocacy, management and involvement on behalf of the person with the ABI

Participants reported the necessity to act as a link between the brain-injured person and services, as well as performing this function with friends and family. In the most obvious of senses this becomes a form of substitute communication, the participant stepping in to ensure that details are not forgotten and full information is passed to others.

My mum always goes with her to the doctors because Lisa will forget what to say or she'll come out and say, "I can't remember".

(Sister 02)

In other cases this is social support, facilitating the injured party's presence and ability in conversation with others when an absence of doing so will create difficulties. Here the partner is attentive to the need to 'communicate for two', to be responsible for higher-level communication that facilitates usual social niceties and prevents impairments to pragmatics of language creating social embarrassment or confrontation.

I do the covering for Andy. So if we're in a situation, I've always got an ear with Andy, so I might be having a conversation but I'm always listening to see what Andy is doing so I step in on his conversations - It's just automatic now. I just step - I'm always hovering around him just to get him out of a situation because I can see him floundering and think it's time to step in.

(Partner 07)

When the person with the ABI lacks insight into their condition it is, by definition, going to mean that they cannot and will not accurately assess the cause of their difficulties and request an appropriate intervention. In these instances it can only be

another party that does this, even if this puts the participant in conflict with the person with the ABI. It is probably worth noting at this point that the individual below, lobbying for specialist services, was simultaneously one of the participants who was instrumental in saving the life of the person with the ABI and also questioned the value of the life of the injured.

One of the things that I've done is with his neurorehabilitation consultant I have written a letter to ask for a referral to a neuropsychologist for him because of this lack of insight and he's unable to make the connection, and he does get very depressed and then of course when someone's depressed they have no motivation and it's a downward spiral. And I do think that actually getting him to talk through that with a neuropsychologist will help.

(Partner 09)

Responsibility for communication, even of a regular more mundane nature, can fall to the participant owing to the functioning of the person with the ABI. Social norms of maintaining contact with wider family and friends becomes a task for the participant when the injured person is unable to do this.

I'm the one that has to make the contact with the boys. I e-mail them and send them – wherever we are, if we're on the mountain, I'll take a photo of their dad and send it to them, "Oh, we're globe-trotting here," all the time just to keep them in the loop so they know what's going on. He can't do it. I say, "Have you spoken to Tim (son) today?" "No." I said, "It's been a week now, Andy. Can you speak to Tim?" "Can't do it, can't do it, can't do conversation." Mum rang yesterday, and I haven't got hands-free in the car so I said, "Andy, can you answer...?" "No, no, can't answer the phone, can't answer the phone." I said, "It's my mother." "Can't answer the phone." No... I don't know what it is, empathy as well, nothing, there's nothing there.

(Partner 07)

This need to act, to communicate on behalf of the person with the ABI can extend to whole teams of staff in some instances. The role of “go-between”, integrating family and professionals was one that was seen as both valued and valuable by this participant. Whilst it is therefore a perceived duty, it is too simplistic to describe this solely as a burden when in fact it can also be perceived as both vital and valued.

I am often the go-between for everybody and between the professionals and the family, which helps them. They are very grateful and I know they are, they do tell me. (Uncle 05)

Knowledge of the need to seek support does not, in the example below, enable the participant to seek it. With knowledge that the situation is without end, seeking support is potentially seen as ‘troubling’ people with concerns that they cannot solve.

*I’m naughty because when... When I need support, when I’m upset, when I’m whatever, I shut down and I don’t speak to anybody. So I’m very naughty. I am very aware of it. Because I don’t want to trouble people.
(Partner 15)*

Family member as key to progress

A number of participants provided examples of where their involvement was required to either facilitate decision making to progress rehabilitation and support or where they were advocating for service provision. Significant progress in this instance was forced by the family in an environment where it would appear that no clinical decision-making or rehabilitation plan was being constructed by the professionals involved. This participant drove a very important aspect of rehabilitation forward for the benefit of her son and at odds with the clinical team.

He kept pulling the feeding tube out, so I went in one day and I said, “Look, he doesn’t like this feeding tube,” and they said, “Well, he has to have it in, he has to have it in, we, you know?” I said, “Well, don’t put it back in this time,” I said, “I’ll feed him”. And they said, “You’ve got 24 hours and if you don’t feed him it

goes back in". I said, "I'll feed him". So I got him eating again and discovered that he actually could swallow.

(Mother 06)

A lack of adequate provision on general or psychiatric wards was frequently mentioned. In the scenario below the young man concerned had made several very significant attempts on his life. His mother was informed that the hospital did not have sufficient staff to maintain constant observation of him, despite their acceptance that he posed serious risks to himself.

Now that was difficult because I had to stay at his bedside because he was so determined, he was still very, very, very determined to kill himself at that point. You couldn't leave him. So I was, I was sleeping in a chair at his bedside in order to prevent him from...

(Mother 11)

Once discharged, the same individual regularly became disconnected from services that were reactive not proactive and, despite the death threats he made towards his mother, she found it necessary to maintain a physical presence in his accommodation when the relevant mental health team regularly failed to do so.

Anyway, so I... I kicked the mental health team back into action I'm afraid, I did. I visited him in his home against their advice initially but keeping the door open, but I did feel relatively safe there because his plan to kill me had always been based here in my house.

(Mother 11)

A less knowledgeable or assertive family member may not have been aware of the role a speech and language therapist may play in assessing the safety of an individual's swallow or the role brain injury plays in impairing this. Lack of communication by staff to the participant meant that pre-morbid functioning had not been ascertained and assumptions were wrongly made.

He got up in a collar and then he was put onto an orthopaedic ward and I said, "He needs to see a speech therapist." They said, "Well, isn't that how David normally is?" I was thinking for goodness sake, he was dribbling, he couldn't eat solids, and he was coughing and choking.

(Mother 16)

The relative's role in preventing deterioration

When specifically asked what they think would have happened to their relative without the support the provided by the participant it was identified that as well as playing an active part in supporting and facilitating rehabilitation and progress, the participant's input prevents deterioration too. It is of note that the literature validates participants' concerns, as research recognises post-ABI deterioration in relation to homelessness, incarceration, mortality and mental ill health.

I do think that if it wasn't for me and my mum... I just don't know what she would have done, I think she'd just be living in some squat somewhere and have no friends.

(Sister 02)

He would be dead.

(Uncle 05)

I think he'd be in prison.

(Mother 06)

If I hadn't been around – I mean I honestly don't know what kind of state he'd be in now, because I was the one who had to do everything from day one because he wasn't in a fit state to do it and because his family aren't around, like there was no one to kind of keep an eye on him. Yeah there was absolutely no way. We've had this conversation so many times since, just saying like if I hadn't been there – and my family were around and they're really supportive as

well, if he hadn't had us then yeah – I don't like to think about it really. But yeah...

(Partner 08)

Participant concern regarding deterioration and the need for proactive input to prevent this is therefore predicated upon sound reasoning. The unavoidability of the burden felt by relatives is, in part, a function of a desire to not let things worsen for loved ones who cannot prevent this deterioration for themselves. This desire to prevent or reduce deterioration (as well as promote rehabilitation and well-being) is very much reflected within practice where relatives are sometimes perceived as blocking changes. As is often shown in hindsight however, this is in fact based upon their specific knowledge of an individual; the risk of deterioration and vulnerability is what drives the relatives' reluctance to agree to plans that do not take this into full account.

Past, current and future losses

The unavoidable burden participants experienced came at personal cost to their previously held goals and hopes, they often were alone with this burden. Participants' spoken and heartfelt commitment is tempered by knowledge of significant personal losses, in the case below the ability to parent or adopt, and also by an avoidance of forward-thinking; a contradiction between a resolute dedication to the individual and a lack of clarity about the future.

I don't know. I don't really look ahead, I take each day. I honestly don't know. Life isn't easy, I'll admit life isn't easy, life is challenging... sorry, I get upset. I don't know, I really don't know. People say, "Will you stay with Andy?" "Yes, I will stay with Andy because I'm dedicated and I'm committed to Andy." I married him and that's it. I wouldn't leave him and I know he wouldn't function if I wasn't here but, I don't know, it's not... sorry, I get upset... I've given up a lot and I know there are things that I can't have that I would like. I would like to adopt but I can't do that. That upsets me. Sorry.

(Partner 07)

Participants' roles and options are curtailed by the unavoidable nature of their involvement with the injured party and the knowledge that if they do not carry out their supportive role, issues will come up that the person with the ABI cannot resolve; things will deteriorate. This is a function of the injury and a function of the participant having no alternative.

Lots of times, why me, this isn't fair, and the other thing that I have suffered with, this is why I have to have my job and I have to have my work, is my lack of freedom, I mean we can't go on holiday, if we go on holiday we've got to leave him with somebody or know he's with somebody, because when we come back something's happened. We went on holiday and he bought a £15,000 BMW, we went on holiday again, he'd had this altercation with these girls and he'd been in a cell overnight and every time we leave him... so we have to take him on holiday with us, so we actually don't get any freedom and I've missed my freedom. (Mother 06)

Sharing the burden

Support and input (formal and informal) where available and suitable was valued but was not able to simply absolve the participant of all responsibility and burden. The participant below retains a significant role in the ongoing support and rehabilitation of his nephew. The support has not removed him from this but it has removed the perceived burden.

I'm happy to hand over (laughing), more than happy to. But that's also what has been nice about the team he has got and his case manager because I can do that.

(Uncle 05)

Where a professional entered the fray and was viewed positively, they are reported as listening, as being 'there' for the relative. The valued professional does not simply replace or usurp the relative but supports the relative in a process of normalising what

is occurring. This is potentially the antithesis of those who the participants learn not to engage with, individuals who do not understand, reinforce beliefs that the injured party and the participant are 'lucky' and who fail to see the bigger picture. Positive input from professionals does not relinquish participants of the unavoidable burden of supporting the injured but they 'share the load'.

I just can't put it into words. We just clicked, I think. In all this chaos, there was this person who came, for me, not for anyone else, for me, and just calmed it and said it was okay to do whatever, to cry, to shout, to have black humour, to - you know, everything was okay. It was allowed.

(Partner 15)

She was just brilliant, she was like a breath of fresh air, because she was listening to me, and she seemed ... seemed to understand what was going on.

(Partner 04)

In this sense ABI again does not 'fit' models of service provision which are based solely or primarily upon the person with the impairment, seeks their views of what is required and does so without the complete engagement of family. Potentially this relates to notions of autonomy and privacy; if so this is predicated upon a belief and value system that sits at odds with notions of reduced insight and with the relatives need to be involved for the benefit of the injured party.

In the example below the injured party has had access, via litigation, to significant funds that have been used to commission and establish a specialist package of rehabilitation and ongoing support. In this instance the participant has been able, over time, to relinquish undertaking practical tasks with and on behalf of her son and to recognise the value of this.

Things like..... she would sit with him, they would break down a task or she would go to meetings with him. She would help him fill in forms, she would go with him to perhaps look at cars or look at houses, and to talk with him to

people when he didn't want to talk to the salesman even though he knows more about cars than you could put. He was embarrassed to do that but he would get her to do it. She was there as a real safety net for him. To make sure that he wasn't taken advantage of. The case manager has been the one, she has been involved with everything, she understands, she's been with David to do things so she will go with him and she can see how he is. She has got the knowledge of what to do. She got the support worker involved and the support worker has been perfect.

(Mother 16)

Participants were able to identify an attitude, those that reduced burden quite simply demonstrated humanity.

So the guys I am talking about positively, it's because they care.

(Uncle 05)

Participants reported that their involvement was an unpreventable necessity. The involvement of the relative comes at great personal cost, an unavoidable cost set against the context of an inescapable grief, where choice about whether to become involved is entirely absent for emotional and practical reasons. Grief is unending, certainty about life goes and ambivalence replaces it. Ambiguity replaces clarity. This process is continuous and enduring and the brain-injured person cannot help and support the relative as a consequence of the injury they have suffered. Services do not and cannot step in to remove all burden and all emotional cost. Specialist services were identified by participants as key, but burden in these instances is not removed by the services but is supported, normalised and given a context.

With the exception of participants whose relatives had access to independent brain injury case management, it was noted that no one party other than the participant (professional or otherwise) took overall and proactive responsibility for the wide-ranging needs demonstrated. Even with access to a brain injury case manager, participants noted that their involvement was required.

5.3.5: Theme 5: The Poor Experience of Support

Difficulties experienced are exacerbated by formal and informal responses provided.

Participants experienced very significant difficulties with services in terms of lack of information, lack of specialism, complete lack of provision offered, excessive length of time spent without support, poor attitude/behaviour of staff, lack of brain injury awareness by services, lack of understanding of the difficulties experienced by relatives, services not taking responsibility for the range of needs present and the added pressure of having to fight to access funding for the services that were available. Participants' experience of the response given by the wider community, including from family and friends, frequently exacerbated difficulties owing to a lack of supportive understanding of both the nature of the injury experienced but also of the impact this had upon the participant. Participant's negative experiences of formal and informal support further isolates them and maintains the grief and ambiguous loss felt. Participants noted that even when adequate (or improved) support was achieved, their lives were still affected by the injury and all that had followed accordingly.

The online survey within this research allowed respondents to rate the services that they had encountered and provide free-narrative responses. It was apparent from these responses (and from practice) that there was considerable dissatisfaction with service provision. This was not universal; some relatives report very positively about some professionals/services. During interviews participants were asked directly about the services that they had encountered and what would improve them (appendix 6).

Poor treatment in hospital

Reports of hospital Intensive Treatment Units (ITU) were generally very positive. This was reflected in the online survey as well as the interviews. The specialised and life saving nature of the work undertaken was highly valued, as was the one to one nature of nursing intrinsic to such units. Once stabilised and outside of ITU settings however hospital provision was frequently described as poor, potentially negligent, with

inadequate levels of staffing, poor communication, lack of basic care and lack of specialist brain injury knowledge or information by staff.

On intensive care I would have trusted them with my life. Then he went on to the orthopaedic ward and they were like idiots. They didn't feed him.

(Mother 16)

The unavoidable inevitability of family input would appear to start as early as discharge from ITU with issues as basic as feeding and hygiene not undertaken by hospital staff. This sense of abandonment and vulnerability at the time of discharge from intensive care is identified in the literature (Chaboyer et al., 2005).

I changed Jake's bed, I bathed him on the ward, otherwise I don't think it would have happened, to tell you the truth. (Mother 03)

Other criticisms related to the level, type and expertise of staffing on general wards.

This is worst bit because the general ward didn't have the facilities to cope with him. And the first night they had him on the general ward we went home and he fell out the bed. And they didn't even know, they didn't even have a qualified nurse who could come and do the suction, you know, the suction they have to do? So they had to bring the nurse that nursed him on intensive care every so often out of intensive care to come and do this, this suction. They couldn't keep him cool, it was, it was the middle of the summer so we had a fan on him, we brought a fan in to try and keep him cool and we did around the clock, and what had to happen was that at night they put a mattress on the floor and he kept crawling off the mattress and so my husband had to go and stay the night with him and sleep alongside him on the mattress and somebody had to be there all the time during the day because they just didn't have the staff to cope. It was as simple as that.*

(Mother 06)

**Suctioning of phlegm/mucus from the tracheostomy to prevent aspiration.*

Such post-injury behaviour is common and to be anticipated and yet a number of individuals reported the same issues, of general wards having no strategy or ability to manage what is a relatively usual response as an individual comes out of coma.

Poor/no communication in hospital

In one instance a decision about resuscitation became known to family, this decision was not taken in conjunction with them or with their knowledge.

They had to restart his heart, I think it was nine times in the helicopter, and his prognosis was, "He is not going to make it." When I got to the hospital, the first thing I did was look at his notes and I am no doctor but it had DNAR on it and I went, "Who the fuck has put that on there? Who said put Do Not Actively Resuscitate?" I don't watch Holby City or anything like that but I do read, I know what things are and they said, "We don't know" and I said, "Well that comes off straight away because whilst he is still able to - there is a possibility of him living." So that was put on there without family consent.

(Uncle 05)

Such a decision, for a professional to unilaterally make the choice to not actively resuscitate an individual with no knowledge of a family's beliefs or views sets up a conflict between staff and family at the outset. Potentially good clinical judgement or opportunity for dialogue becomes lost, services and family are segregated not integrated.

Some participants identified that they were not informed of the brain injury at all, others had to search for information, even whilst the injured person was still in hospital.

I don't understand how he can have been in the hospital for six days and had two brain scans and no one would have thought to themselves, "Oh this could have long term implications". I mean to be honest, I don't know. (Partner 08)

The only contact I had with regards to brain injury was there was a scrap of paper with the Headway number stuck on a notice board. End of story. And in desperation, I phoned it.

(Mother 14)

Participants noted that the prognoses they were given by medical staff for issues of life/death (not outcome) were overly pessimistic and inaccurate. Where participants had been informed of likely long-term disability (in particular regarding cognition, behaviour and functioning), this was noted by some to have been accurate and by others to have been considerably worse than in actuality. There appears therefore to be a contradiction in the evidence provided by both respondents and participants with regards the information they required and/or were given at the time of injury with some stating the information provided was overly pessimistic, others that it was overly optimistic. A number of individuals reported being given little or no information whatsoever. Participants recognised that information was however key to their situation and they valued its accuracy as a basis for future planning and adaptation.

Without the information you can make the wrong plans as well. If you know where you stand right from the beginning, I just think it puts you in such – a much more powerful position to be able to make the kind of changes you need to make so that you can get on with your recovery.

(Partner 08)

Criticisms of hospital treatment tended to focus on issues of poor care, poor communication, not being informed that a brain injury had occurred, not being informed that a brain injury may have a longer term impact, not being followed up, not being involved in discussions and of being placed on wards that were not established to accommodate the needs of people with brain injuries, in particular to not be able to cope with the common behavioural difficulties that are experienced as a function of the condition.

Poor professional practice and lack of understanding

Post-discharge from hospital, participants' stories told of poor experience of services and of individual professionals. Every participant was able to report perceived poor practice in a variety of arenas including difficulties experienced with rehabilitation services, social services, education, community support services and with General Practice. Frequently these issues are unresolved and enduring.

Their complete lack of understanding. I did complain about a social worker actually. The way she treated us. And she actually came and apologised and then she actually came and told me that she was taking up some training on brain injury and I said, "Good". They don't have any training in it. And the other thing that, the other people that don't have any training in it is the GPs. Absolutely nothing. They want to prescribe and send you away.

(Mother 06)

Involved participants were sometimes perceived as overly controlling or 'unable to let go', their knowledge not be recognised or accepted by professional staff.

The worst problem is the cognitive stuff, which you kept saying he's not right; he's not the same. "You are imagining it, you are a mother." No, I do know my own son.

(Mother 16)

Participants had a nuanced view of 'hope'. None believed that a miracle could occur but their hope sometimes put them at odds with professionals who potentially viewed hope pathologically rather than as a state that enabled family to continue, against the odds and without support (Mattingly, 2010).

He said, "Oh, we didn't have much hope" and stood up and showed me out of his office and I thought, "You're dealing in mental ill health. Severe mental ill health and if you can't ever give anybody hope, what are you giving them?" It

was just such a dis- such a- I actually felt sick when I left. It was like getting punched. (Mother 14)

A lack of professional understanding, in the case below, of the law pertaining to Mental Capacity and the Deprivation of Liberty Safeguards was found surprising by this relative who undertook a little research and became more knowledgeable than the statutory social work team involved in his nephew's care.

It was very surprising for these people who are paid professionals and it takes family members like myself to point out the basics.
(Uncle 05)

Lack of professional responsibility

Shifting responsibility for the care of difficult to manage individuals from the hospital to the family sometimes took place without a meeting; practice around discharge from hospital was almost universally held as poor.

And then because he was walking and he was on his feet and he was, you know, they had a big meeting and they wanted him to, wanted us to send him home and leave me to deal with him.
(Mother 06)

Non-specialist services with little or no knowledge of ABI are under-resourced to manage extremely complex scenarios (Wurr, 2012). The participant is then cut adrift from formal support whilst being aware that they have to remain involved to prevent deterioration.

And there was nobody coming to help. I asked the social workers to come, they came from older people' services and she said to me, "Oh well you seem to be doing a good job and you're a therapist so you know more about it than me," she said, "you know, we haven't got the resources for the old people let alone this". (Mother 06)

Failure to include the injured party and the relative

Participants were able to recognise that rehabilitation and support services need to be very individually focussed and that a failure to do so belies a lack of understanding of how to engage people with an ABI and work more effectively. This is very much reflected in the specialist ABI literature (Clark-Wilson et al., 2014, Ylvisaker et al., 2008).

Terry Smith was a person that mattered and that was relevant and continues to be relevant in who he is today, so the people that don't get that actually don't understand neurorehabilitation in my mind.

(Partner 09)

Participants were critical of services and professionals that did not include their knowledge of the individual, of what their preferences were and of how they had changed as a consequence of the brain injury. Such an approach is criticised in literature that identifies that an individualising approach negates the reality of family life and experience (Yeates, 2007, Newnes, 2006) where a more systemic approach is recommended. Participants simply not being believed about these changes was also a feature.

I know, yes, they do it to make sure people are telling the truth and honesty but you sit there, pour your heart out to people and they treat you as though you are liars, basically, that's how they make you feel and I'm as honest as the day is long and Andy is too and I pride myself on all the way through my life how honest I have been and am, and they just make you feel – you are sitting there with consultants and they questioning as if to say 'you are making that up'.

(Partner 07)

I think because no one was interested in who he was or when people even say to me now, the consultants, "Oh, but isn't that just part of his personality?" oh god I want to slap them, like "No, that's nothing like his personality actually."

Again no one was interested in my opinion because I was just obviously the wife of this person and what did I know? (Partner 09)

Notions of confidentiality, data protection or 'human rights' were seen by participants as excluding them from the conversation and plans that were required to meet their family members needs. Family were sometimes expected to take responsibility for the person with an ABI but felt excluded from the dialogue regarding this.

Confidentiality. It's a huge blanket. It's a war. It's a weapon. If I have ever- if anybody says confidentiality, I say, "Look, there's no point in worrying about our Sean's confidentiality. His life is decided by strangers who know everything about him" What's there to be confidential about? He needs help. We need help. I will stand on the top of the Empire State Building and broadcast my entire life if I thought something could be sorted out for him.
(Mother 14)

Services sit outside of the family system pre-injury (naturally) but, when they are not perceived as working, they continue to sit outside of the system post injury too. Other people are not integrated into the family-system, reinforcing the sense of being alone for the relative. The nature of ABI is such as to make it highly unlikely that the brain-injured person can adequately advocate for their own needs. Involvement of family is therefore essential to tailor rehabilitation and support services to the individual family, to make the response specific and bespoke.

Participants noted that poor experience of professional input was based on numerous factors but these included a lack of understanding of pre-accident functioning and personality, a sense that the relatives were not believed when describing changes and/or behaviour and that all difficulties were presumed to be pre-morbid in nature. Participants described having their knowledge excluded from discussion and plans and of being made to feel (or actually be accused of) being over-protective, with notions of the injured party's "confidentiality" being used by services to prevent adequate and needed action. Participants described not being allowed to either provide or receive

pertinent information regarding their injured relative, despite the fact that they were often sole carers and/or when the impact of this decision related to individuals with questionable capacity to give or withhold consent regarding their own needs, often as a consequence of reduced insight into their condition. Participants report that professionals, sometimes with little or no brain injury experience and no knowledge of how a person functioned pre-morbidly, make assessments, decisions and plans relating to the injured party nonetheless. Often participants disagreed with these decisions.

Poor attitude/behaviour of staff

Perceived attitude of staff was commented upon by participants as being a negative part of their experience, exacerbated by poor communication.

Some of the nurses on the stroke ward were less than wonderful. I found, I actually, actually caught one nurse scolding him for asking the same question repeatedly, she said, "Why are you asking me where you are? I told you ten minutes ago. Why are you asking me again?" And, you know, "What are you, stupid or something?"

(Mother 11)

People with an ABI in a post-coma state, post-traumatic amnesia (PTA), are unable to take on board new knowledge and retain it. Very repetitive questioning is therefore the norm. It would be considered good practice to answer the same question, repeatedly, as if it was the first time it had been asked and to provide visual supports, such as a noticeboard with date/location on it. This reduces anxiety and may enable the frequency of questioning to be reduced. More than one participant noted that nursing staff accused their relative, still in a state of PTA, of being 'stupid'.

A lack of interest in the individual, of seeing them beyond their diagnosis, was perceived by participants as evidence of a lack of care.

Be prepared to take the time to find out more about Peter and people who really need to know that he's not been stupid and thick and all the rest of what

he's been called over the years. It's not a very nice thing to say but I've sometimes felt like saying "You're the stupid one, you're the thick one." Because I've never asked any more than... "Okay, I understand that you don't understand, but at least try" yeah?

(Mother 12)

Because you get wasters wherever you are, you know. And I do understand that too but you know, you can go and waste time somewhere where it doesn't matter to somebody's life. I know it's a cliché but you can go and stack shelves somewhere if that's- because some of them- and I'm totally sympathetic with the fact that they get paid piss all for a difficult job.

(Mother 14)

This introduction to a UK hospital was recalled with clarity over twenty-five years after the event.

When we came back into the UK, we actually – it was horrific. We came into the city, we were wheeled up the – Graham was wheeled up the corridor and he was placed on the bed and the Sisters' first words were, "Now, in America it might be different. Visiting hours here are..." Her first words. We had travelled without sleep, without anything, we hadn't slept the night before, we left at 6am, we headed for the airport, it was just an absolute horror. And so she went away and I stood there thinking, gosh.

(Mother 13)

Similarly the dehumanising use of the words "a hanging" to describe this participant's son, rather than using his name, has remained with this mother for over a quarter of a century too.

Lots of people saying either nothing or cheerfully saying, "No hope" or one nurse described how somebody- they kept referring to him as "a hanging." "We

find with a hanging-" you know? I think- not an appropriate word to be using to me. (Mother 14 – brain injury caused by a suicide attempt)

Participants noted that the style of communication used by professionals, the words they used and the perception of control and power behind them affected how this communication was received by them.

There was a lady there from CCG (Care Commissioning Group), who was dreadful. She, half way through the meeting, she turned around to me and said sorry, what was your name again? Even though we had all introduced ourselves. (Partner 04)

When coding the transcripts to create the data regarding the participants' experience it was notable how poor experience of service was firstly clearly recalled and secondly perceived to have a negative impact upon the treatment, recovery and support of the injured as well as upon the participant. This stood in sharp contrast with the positive experience participants reported in terms of both professional and other support received, to such an extent that they developed as entirely separate themes.

5.3.6: Theme 6: Positive Support and Change

Positive change can occur and this can be supported by formal and informal structures; the relative plays a part in knowing how this can be achieved.

Participants recognised the importance of their knowledge and input in supporting their injured relative, seeing the pivotal part that they played in facilitating rehabilitation, positive changes, support and adaptation to injury. Participants identified aspects of service provision and individual professionals who they reported were positive and constructive elements in their own journey. Professionals that enabled participants to be more effective with their input were held in high esteem, and gratitude was expressed for the knowledge and approach taken by them. Some participants also noted that they received support from family, friends and the wider community that was very much appreciated and without which they could not continue to support the injured party. Notwithstanding the serious and significant distress experienced, participants were able to recognise their strengths and resilience and view themselves as being part of positive changes be these functional ones, ones relating to increased acceptance of the unavoidable consequences of the injury or of personal growth and learning through adversity. Positively reported upon professionals acted as a supportive catalyst for this process. Participants' commitment to being involved in this research was predicated upon their desire for services to change and improve for the benefit of other families.

Specialist knowledge and approach

All participants reported positively about some aspect of a service or an individual professional, notwithstanding the significant difficulties that were reported in theme five. The benefit of specialist knowledge, facilities and abilities was commented upon.

A lady from Cambridge, she's a female surgeon who has got a wealth of – she's educated really on – such as like Jake. Never met her in my life. And an expert report was done from her, which I got, about eight pages long, more in the medical terms obviously with her knowledge. Me reading that and what she put

in that and everything, I felt as if she'd lived with us for the last 12 months. It was unbelievable. (Mother 03)

She (BICM) was the person that seemed most connected with the changes that had happened to him. She knew the things that he was finding difficult. She knew ways that he would be able to cope. She talked to him about ways that he could manage with the difficulties that he was finding.

(Mother 11)

Both of the above quotes relates to comments made about specialist brain injury services or professionals. Participants are able to identify this knowledge, this ability to connect and the value of such specialism.

Empathic flexibility and understanding

Whilst some of the praise for and recognition of the value of professionals was about the outcome of their input, much of it was more related to process. Specialist knowledge and experience was highly valued but so also was attitude, approach and genuinely including the participant. This was reported as the relationship starting from the perspective of the family and not from a professional viewpoint: changing the service to suit the family and not the other way around.

Lisa's very set in her ways and she doesn't like using anything except a 9B pencil and she won't do this, that and other, and the teacher, she's recognised that already.

(Sister 02)

Services that changed to suit the needs of the individual were valued, in this instance Lisa would not stay in an art class unless the teacher adjusted her approach to suit her needs. This has been very successful and has given Lisa activity and meaning. After decades of having little purpose or structure, Lisa sells her artwork, has increased social contact and a partner. Life is still changed and very difficult but the driver for

these changes is perceived as a flexible art teacher who adjusted her approach to suit need.

Empathy is valued, the notion that the professional understands the situation the participant finds themselves in is key to relationship forming.

The social worker actually is another person who has been amazing, very young girl, but she just really understands and really gets it.

(Partner 04)

As participants described far more in the way of difficulties, far fewer professionals that they perceived as understanding, those that were considered positively were very much valued and humanised.

Practical and dynamic assistance when required is recognised as being very supportive. One participant spoke to a residential rehabilitation unit manager every day for a lengthy period and he was able to reflect upon the fact that this was what made the difference. Others noted that professionals were not valued for outcome, for creating the impossible. Process rather than simply outcome is valued, humanity and a sense of connection with a professional who may also be lost and unable to provide an answer.

The social worker who- I mean, I couldn't fault her, the girl- she couldn't provide services that didn't exist. And what I can say about her is, she sat and cried with me on occasions because I was in bits and- just soft, soft girl.

(Mother 14)

An attitude, above and beyond outcome, perceived as caring and recognising the relative's situation is valued.

A lot them do help us. It is like look at the psychologist, he is a professional at his job, but he took time out to understand, do you know what I mean? There is

a lot of them that like ... what do they call them? Like pen pushers, ain't they?
(Partner 01)

She (rehab unit manager) was the person I was on the phone to for an hour every night for that first six, seven months.
(Uncle 05)

Taking the time to understand, to see that as a necessary component of the professional's role, was recognised as central and valuable. Such professionals take on board the positive impact that working at the participant's pace has, acknowledge that ABI is a process not an event, and recognise that it is a process for the relative every bit as much as it is for the injured party.

The case manager, she has got to know Robert so she does know certain things, don't she? It is like because she has been in our life for like two years. She helped me as well, when I was going through my thing.
(Partner 01)

David had a speech therapist, one of the private speech therapists, she was lovely she rang me up about a year ago and I was very upset and she said you really need some help, hasn't anybody spoken to you, and they hadn't. I think the parents really need somebody that they can talk to. It's not somebody who is going to give you an answer, it's just somebody to understand and say "yes I know".
(Mother 16)

Participants valued the inclusion of their needs, in particular emotional needs within the empathetic professional's role.

Practical and caring help

Similarly with non-professional input, be that family, friends or neighbours, was noted by some to be a very real and invaluable support for participants. Whilst a component

of this support was practical in nature, the sense of “moral” support was also prevalent with notions of individuals “being there” for the participant.

In this instance the neighbours have slowly increased their practical support, initially by cutting the participant’s lawn (unasked) and running errands as she copes with having a profoundly disabled husband residing in a specialist unit (an hour’s drive away, she visits most days) and two young children at home.

The neighbours have been brilliant. Practical help, yes! Babysitting when I have needed to visit Simon and mum and dad have been away, like last night. And support actually, because they are friends. The two opposite me are really close friends, yes.

(Partner 04)

The behaviour of the individual below is such that for the last fifteen years he has been resident in a specialist secure setting where he initially received two to one staffing support because of his violent outbursts. His family coped with him at home for ten years before this and neighbours regularly played their part, even in the early hours of the morning.

We have a rare group of friends and some of them – one of them was the Methodist Minister who actually lived quite close and he was brilliant; he would have come past, he would have come round for a walk and if the lights were on in the attic he knew we were in bother. So he would have come – he would come at 12.30 at night and wander round and he’d have come in and sat with either one of us while the other sorted out as best they could and then we would change. He was lovely and we are still very friendly with him. And another man who wasn’t connected with the church and he would have done the same. He would have taken a wander or we could have phoned him at 2am and said, “We are in terrible bother here,” and he would have come and he was lovely but he was a friend who lived nearby. I think it’s very hard for a stranger

to come in and actually tune in to what it's about and how... I think it's really hard.

(Mother 13)

Some participants identified that, particularly close to the time of injury, they had received very significant support from wider family, individuals who abandoned their work, travelled great distances and provided financial aid as required. The injury takes place to an individual but the impact resides with the wider family and community.

Truth telling

Rather than specific information, that may or may not prove to be accurate, participants benefitted from knowing that things would not be as they were before the injury.

He also helped us – he put a plan in place, he was like, “You know –” he just gave us really good advice. He was like, “Your life isn’t going to be the same” and this was the first time anyone had ever said this.

(Partner 08)

The most important thing is knowing from the beginning where you stand and not – by not giving people the information, I think it gives them false hope that it's going to all get magically better.... I don't think it does anyone any harm and it does a lot of good if people, from the start, know this is a big deal and it will probably change a lot of aspects of your life and the sooner people can deal with that, the better.

(Partner 08)

Participants identified that some of the information given to them was very unwelcome, but that they benefitted from and were supported by being told this information clearly and as soon as is possible.

Support is somebody who helps you in the situation in which you find yourself. That helps you to, helps you with coping strategies. I mean, from my point of view, I was needing to, I was wanting to help Owen, and she was saying things that I could do to help him and things that he could do to help himself and from my point of view the only thing that I could do really was remind him when he needed reminding but that's something helpful, do you see?

(Mother 11)

Including the relative

Participants spoke about “learning along the way”, that their experiences had unfolded over time and they had been a part of accruing and adding to knowledge as part of this process. Participants recognised the value of being included and of being prepared for the long-term nature of the injury, in this instance when a son was injured in the USA and initially treated there prior to returning to the UK.

And in the hospital (in the USA) you were – and it's a very different set up, you were included, you were told exactly what was going on and they sent you off – they cared for you as well as the patient and they realised that you had a loss that you were going through. And they told us – one of the surgeons, he told us in no uncertain terms, “You are in for a long haul with this and there's no ‘suddenly better’.” So we knew that when we left America.

(Mother 13)

Positively reported upon professionals learnt with the participant as the reality of the ABI became clearer over time, each party bringing an aspect to this process.

She has learnt a lot along the way as well.

(Partner 04)

Personal relationship with professionals

Words used to describe the valued professional step outside ones more usually expected of those between a client and professional. Participants spoke with genuine

warmth about key individuals, using words such as “amazing”, “love” and “lovely” and described staff who went beyond their anticipated roles and acted with empathy and imagination, some described unconventional or even eccentric staff. The most valued staff are referred to as unforgettable and are frequently referred to by first name (excised here).

She's down to earth. She's a bit crazy too. She's just special. She's just – I can't tell you. She's just fab.

(Partner 15)

The personal connection made, the sense of a proxy or pseudo-friendship is apparent albeit the participants recognised that this was still a professional relationship.

I love the day centre manager, she's great. Do you know she makes no money out of her job, in fact she supports it out of her own pocket. She works with her heart, not with her head.

(Mother 06)

Family members recognised when professional staff went beyond what would be considered the norm, working with passion and commitment.

And the psychologist said, “Yes, we'll take him.” And we thought, “No way.” And eventually he went; he went after two or three weeks. And we used to go over to see him and he had taken the doors off wardrobes, he had broken beds, he smashed toilets, they used to be lined up. And their way of looking at it was, well, what's the answer to this? So the broken toilets was they sent somebody to Holland and they came back with a stainless steel toilet because they couldn't get one in England so somebody flew to Holland and brought back a toilet. And in went the toilet and that – they are so zany. The owner is an absolute – oh, he is an incredible character, but he – their philosophy was we will build it right, what he needs.

(Mother 13)

Despite being placed in a highly specialised unit this man continued to exhibit very violent and difficult behaviour. This was addressed iteratively and slowly as the unit learnt to understand him and the antecedents to his violent outbursts. In this example the provision of an imported stainless steel toilet has overcome one difficulty but the approach, one of changing service to suit the needs of the injured party, is what has allowed for significant behavioural change and improvement to functioning; the service changes to meet the client's needs and not vice-versa. There is no existing service that can fit such needs; it has to be built bespoke.

One participant physically described a professional, how he looked and acted. He was not able to provide her with answers or with a service that helped her son but his attitude, humanity and openness meant that she recalled him fondly over twenty years on. Of the hundreds of staff she has encountered in the 25+ years since her son was injured, most were unremembered but this solitary event of no more than ten minutes duration was recalled with great clarity.

He asked me what the behaviours were that were upsetting people. I says, "Well, he laughs inappropriately" and I always remember this, he says, "Well," he says, "In here, I laugh inappropriately" and he started laughing. Course our Sean went into hysterics. Three of us were sitting in his office with tears dripping off us. And I just- you know, you just met somebody that is clued in. He was a lovely man.

(Mother 14)

Valued staff and services are described as going beyond what may usually be expected, services adapting to meet the needs of the brain-injured party and the relative. Valued staff can border on "being part of the family". They are not strangers but are familiar at least, even if not familial, and they incorporate the needs of the relative into their actions, knowing what is important to the relative.

And then she just – oh, she’s naughty because she’ll look at you – she knows if you need to cry and she’ll look at you until you bloody do. I tell you, I tell you, she’s just... I can’t describe her. She’s an amazing person. Everybody should have a Headway nurse, you know. I didn’t know her before. She’s just – honestly, I can’t even put into words.

(Partner 15)

The supportive professional sees a bigger picture and understands that the treatment of the participant has an impact upon the care and needs of the person with an ABI.

I can have an appointment with the GP for Andy and I get one straightaway whereas normally you have to wait for appointments. They are very supportive in that way and I think they’ve supported me in that there’s waiting lists for everything; when I had my knee done I was in like that and I went to the private hospital and they got me in and I’m sure it was to do with Andy.

(Partner 07)

A large and privately purchased team (via litigation) is engaged with family sufficiently to be aware that continuity of service and trust is greater than the fine detail of contractual arrangements.

A lot of the agencies that we’ve been working with, the multi-disciplinary team members, a lot of their companies have been waiting for money for ages. So we’ve had it where we’ve been indebted to them and they are still continuing to provide their services because they understand the situation.

(Uncle 05)

Valued professionals include the wider family in rehabilitation process, normalizing this for children and adjusting their plans to do so. Participants identified staff who changed their plans to suit family involvement, including children in engaging physiotherapy sessions or altering the focus of work as family need changed.

The necessarily intrusive nature of service provision, particularly when over extended periods, inevitably alters relationships from simply service provider and family/purchaser.

My sister is kind of getting her head round that. I said, "Yeah, look, everyone is paid. You're absolutely right. So if there is an issue and you expect something to be sorted out then it needs to be done and it will be sorted out." However, you've then got to approach – you can't have people round your house having cups of tea and a good chat and then when it suits you to pull the cord and say, "No, no more. I'm unhappy today so therefore I'm going to have a totally different attitude with you." It's not an employee - employer relationship. You are part of the family really, effectively.

(Uncle 05)

Professional staff taking the time to understand what is important for the family member was key in the example below. It was notable that the participant below described how other staff did not make this effort, seemingly unaware of why this call was important. The injured party was twelve years old, his extended time in hospital was his first time away from home.

There was this one nurse that was ready for my call to tell me what had happened in the night, and that was a huge weight off my mind considering that was seven o'clock in the morning just before she went off-shift and I wasn't going to see him until three. I really needed to know how those hours had gone, and she made a big difference knowing that it mattered to me.

(Mother 03)

The reality of severe brain injury is such that "cure" or a total restoration of pre-accident functioning is unlikely and so the nature of the experience is one of transformation for the relative as much as for the injured person, adapting where possible to new if unwelcome realities. Professionals without specialist knowledge and/or those who were unable to affect any positive change in terms of access to

rehabilitation or support for the brain-injured party were also sometimes valued and played a positive part in the story told by participants. This occurred when the attitude or approach of the professional was perceived as recognising the position of the participant in their impossible to resolve grief.

The valued professional bears witness to the participant's reality and this is perceived as a relationship. In some cases this is a very temporary relationship, in others this is a durable one, where consistent professional input has lasted for decades.

Whilst discussing the injury and the impact it had upon the participant and their relative was upsetting for nearly all, participants spoke with hope that their involvement in research may improve services for others and had ideas about how professionals or services might be improved and their experience normalised.

Relatives' views of what needs to improve

Discharge from hospital was almost universally criticised as being a time of poor and disjointed service provision. Gaps in service occurred and participants' assumption that this communication would take place between agencies without their intervention was found inaccurate.

I think that's probably where the handover from the NHS to the Social Services needs to be better, needs to be clearer.

(Uncle 05)

Participants feel duty bound to be involved, their input is often essential and yet service provision, if there is any, does not take account of the needs of the people that often undertake the bulk of the support.

Well it's the whole care package, isn't it, it's not just the care packaged focused on the person, it's focused on the people that are looking after that person.

(Mother 06)

Lack of understanding by professionals of the actual impact of ABI, most especially executive impairment and loss of insight was commented upon. This lack of understanding impacts upon the assessments made by professionals and their ability to accurately empathise with relatives (Holloway, 2014a).

I think the only way it will improve in the future is if people are aware of... aware of what happens. I don't think people understand executive dysfunction.
(Mother 11)

Knowledge, empathy, concern and context that normalises the participants' situation is considered a key component for supporting relatives.

I think it is having somebody who you can just ring up and say this is how I feel and then they will say yes; I understand that, that's normal. That's all you need really, perhaps.
(Mother 16)

Participants' and respondents' commitment to being part of the research was predicated upon their desire to see services improve for the benefit of others.

It does affect me. I know I get upset talking to you but it doesn't matter because if you can make some difference to the NHS it will be worth it.
(Mother 16)

Participants reported that their own adaptation to the unwelcome changes brought about by the injury to their relative benefits from outside input and this input is valued. Participants valued attitude, knowledge, availability, information, concern, specialism and caring involvement, potentially above outcome, supporting their adaptation as well as the rehabilitation and/or support for the injured party.

5.4: Overarching theme: The Curator of Narrative

Overarching everything, the relative is key to holding the narrative threads of the past, the present and the future. They are alone in being able to perform this task.

Owing to the nature of the brain injuries suffered by the person, they are highly unlikely to be able to accurately describe their pre- and post-accident history in as much detail nor to be able to project into the future as well as the uninjured relative can. This loss is a function of ABI. The interviewed relative therefore holds historical information and knowledge that is not cogently held elsewhere. They are witnesses to the shattered narrative and changed identity that severe brain injury brings and, as the only party as closely involved and over a long time frame, they are the only individual to hold this knowledge and maintain historical continuity to this extent. This is particularly but not exclusively the case when considering the knowledge held by parents of brain-injured people. The stories told by the participants have a clear “fracture” at the point of injury, one that defines the present and future and sets the pre-injury past aside as a separated time that is not recoverable; it is disconnected. Relatives hold onto this story, guard it and nurture it and do so out of a sense of complicated love despite the burden and damage that doing so does to them.

During the thematic analysis of the transcripts the notion of ‘narrative’ developed as a theme. Whilst each participant had their own story it was always inextricably interwoven and integrated into the story of their injured loved one. Interviews moved back and forth in time, chronology referred to but rarely adhered to, these narratives journeying from location to location and back again, pre-injury personality and experiences forming the lens through which post injury functioning was described. For those with 20-plus years of experience, understandably perhaps, accuracy of chronology meant less than the description of a trajectory of a life.

Sorry for going on. I mean, you shouldn’t encourage me, like. And I know I hop all over the place because I’ve been all over the place.

(Mother 14)

For those with 2 years experience only, chronology appeared more stuck and specifically named dates and details stood out clearly, as did the sense of unreality that more recently experienced grief brings. *(Dates changed)*

It was on the 17th of April 2012. Simon had been complaining of headaches and neck pain, for about five days. At the weekend, on the Saturday, it was the Monday morning that he had the stroke, but on the Saturday he had a headache, and then Sunday he wasn't too bad, it was Mother's Day, and we just had a nice family day.

(Partner 04)

Just as the story of time and place oscillated as the participant endeavoured to ensure that a complete story was told, expressed emotions wavered as the story of the impact of the injury upon the relative unfolded. Reviewing the story as a whole gave participants the opportunity to recognise where they were compared to where they had been before in terms of their own knowledge, understanding and acceptance of/adjustment towards the injury and its outcome. Such narratives were however not complete, there was a sense of traveling towards understanding, improvement and the unclear future.

If I had looked back four years ago, I would have never have thought I would be the person I am now.

(Partner 04)

With few exceptions the interviews provoked tears. This happened when recounting the process of injury and the early days in hospital when staff voiced that death was a real possibility, when participants spoke of the losses they and the injured party had suffered and also when giving voice to what may be upcoming. Expressed grief therefore resided in the past, the present and the future. For two individuals, mothers each with more than 20 years experience of having severely brain-injured sons, their tears caught them by surprise to such an extent that they both noted that they had not

expected to cry; it was giving voice to the whole story that caused this, a reminder of a painful past and its implication in their complex present.

If you didn't laugh you'd cry, you know? And I have done a lot of that. I don't do it much recently, only when I start reminiscing and think of the whole journey.
(Mother 14)

For another two, partners of men injured much more recently and who had yet to return home (owing to issues relating to funding, an unlikely possibility for one of these men at least), grief was firmly focussed on the future, both women crying for losses that were yet to occur but the horror of which it was possible for them to begin to predict as they spoke; their grief for their changed futures commenced as they created their likely realities in words. What they could predict was uncertainty, an absence of the clarity that they required.

And even like his funding has been agreed, although I know it is ... it has been agreed, it is still going to get reviewed on an annual basis, and me and my 'worry head' is now thinking what about in a year's time?.....I keep finding another excuse, not to kind of have to think about me, and be on my own and ... what do I want? I don't know. Getting to a new chapter I think. But it is not knowing what that is ... it is the unknown and uncertainty.
(Partner 04)

Participants were the keepers of this history, they alone were the only person who could possibly hold all of the threads. Other family members and friends had faded from the life of the injured party and, even for those who described being well supported by family or friends, the support was directed at them and not the injured relative. Participants were the connection to the world for people who had become partially or wholly disconnected from it by virtue of the impact of their injuries. This connection to the world, this marshalling of history, is in itself an endless responsibility for the relative.

This is a lifetime situation, it's a lifetime situation.

(Uncle 05)

Curating the narrative of another is a burdensome task but one that only they can and will do, it is done for reasons of love and to support their own interrelated needs and narrative.

He's my son and I wasn't going to give up on him. And I would have had anything rather than nothing.

(Mother 06)

So the relative is central to a story, to the creation of a history that only they could have constructed and told/retold. They are the "I" in the story that only they can narrate about another. Without them there is no continuity from the past to the present and the future. They are keepers and guardians of a history that has been altered beyond recognition, beyond understanding and perhaps beyond other people's care or concern. The nature of brain injury is such that responsibility for this story passes from the brain-injured person to the relative.

I mean they completely mucked it up; they got the whole story wrong.

(Partner 09)

The story, as it inevitably must, develops but does so without a known context or path. Without appropriate support it is left unshaped by those outsiders who could positively develop this, it is potentially frozen at the worst stage of trauma and grief.

Where professionals entered the story they often evoked strong emotional responses, being brilliant and cherished or hated and despised. Relatives with longer histories noted that the middling and mediocre were simply a blur, unremembered and unnamed, roles not people.

It was just daggers drawn and she was very rude when she came to the house and she would sit and take out a sandwich and she would leave her wrapper down the side of the chair and all sorts of things and I thought, "I can't stand this woman coming to the house any more"

(Partner 10)

The brilliant and the hated professionals were remembered well. They entered the story and formed part of the plot, something to be fought against or embraced. The embraced, noticeably, had first names and less often were referred to by role. Those against whom battle lines were drawn were defined by role, roles which limited and depersonalised them; those that were not part of the solution becoming part of the problem.

She (social worker) was a good one to have on your side. And I felt very much she was on our side. As best as she could in the circumstances.

(Mother 14)

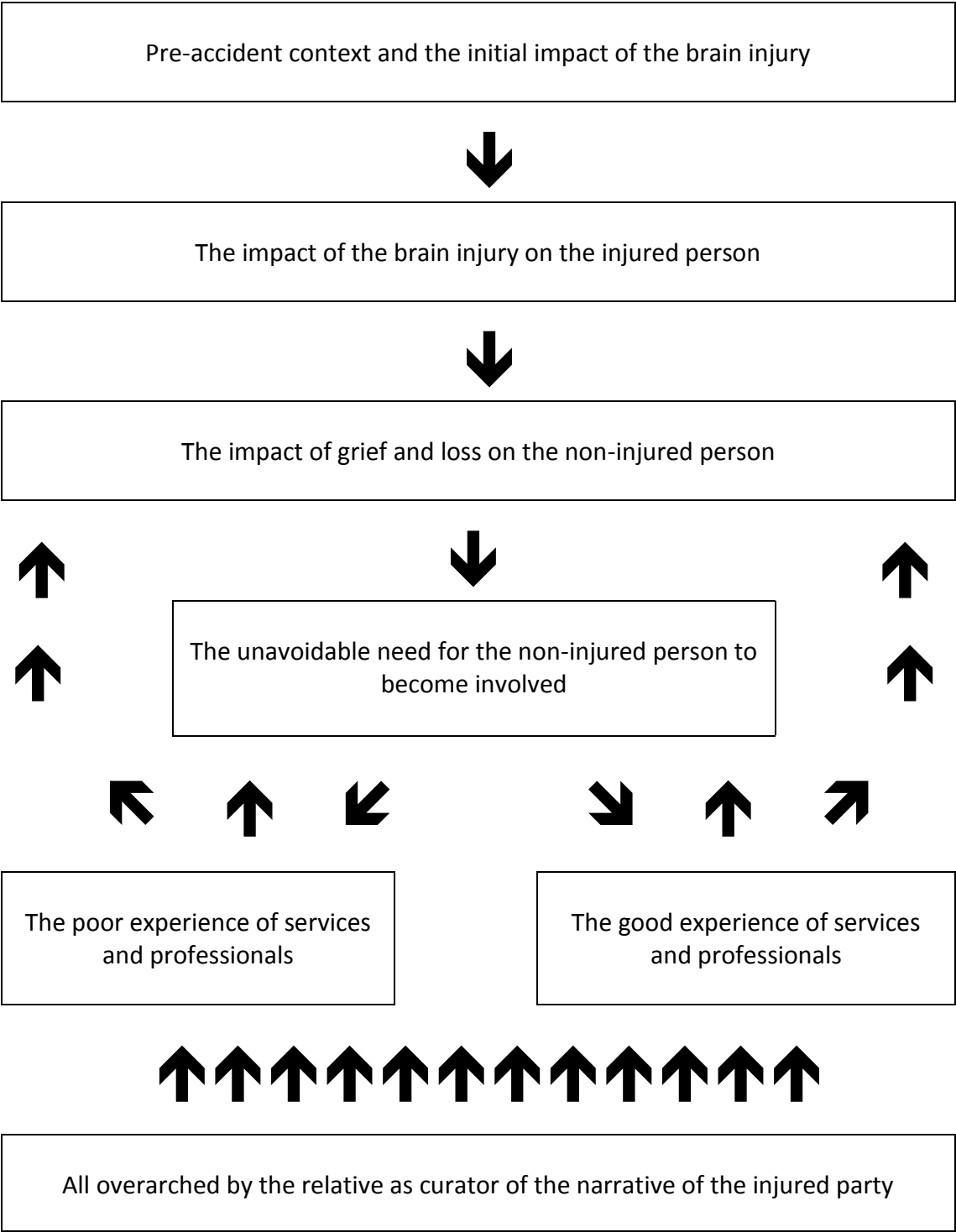
There was therefore a sense of "story", of chapters within this, of characters that enter the plot and of responsibility for the overall narration resting with the family member; the only person who could tell this story. Use of words such as 'chapter', 'journey' and 'story' by the participants echoed with my understanding of the power of narrative in our understanding of our lives and, in particular, in relation to matters of trauma and illness (Todd and Weatherhead, 2013, Ulatowska et al., 2013, Shapiro, 2011, Charon, 2006). At points participants looked to be using narrative to understand the plots and situations they found themselves in, to re-create life after such a profound event (Butera-Prinzi et al., 2014, Easton, 2016, Mattingly, 1998, Mattingly, 2010). They are the (indirectly and directly) 'Wounded Storyteller' (Frank, 1995).

Themes summary

The separate but interconnected themes are presented diagrammatically in table 19.

Family members describe how the context of the accident has an impact as to how this is experienced and felt by them and their injured relative. The nature of such injuries affects all aspects of the non-injured party's life and leads to their inevitable involvement in a myriad of tasks, from basic day-to-day management and practical support, to behavioural and emotional support and liaison with outside individuals/authorities. Family members' experience of formal and informal support structures impacts upon their experience, their grief and losses, which in turn affects their involvement with the injured party. Overarching this is the theme of the relative being the only party who holds the injured person's life-history together in a cogent way.

Table 19: The Themes: Construction and Connections



Chapter 6: Discussion: Research Synthesis and Recommendations.

The seven inter-linked themes, in combination with the quantitative and qualitative results of the online survey, describe the complexity and far-reaching impact of the relative's experience of ABI. In this chapter I engage in a further stage of abduction, linking this experience to specific mechanisms identified in the literature that may be contributing to the outcomes described by informants. From this, I suggest how these findings should serve to shape the style of response and services required by family of people with an ABI. Integrating the relatives' experience this way supports services to focus upon what works from the relatives' perspective. In the previous chapter, for example, it can be seen that the outcome for relatives, the distress they describe, is mediated by the mechanism of ambiguous loss which is set into the context of the societal response/lack of response to the injured party and affected relative (Pawson and Tilley, 1997).

6.1: Ambiguous Loss, Information, Knowledge and the Provision of Prognoses

Relatives reported clear, complex and enduring grief in line with research regarding ambiguous loss and ABI (Giovannetti et al., 2015, Godwin et al., 2014, Boss, 2006). Despite the very unwelcome nature of these changes, relatives were aware of their reality. Simply believing that the clock could be turned back or a miracle would occur did not feature in the data collected, except when acknowledging that it was not possible even if strongly desired.

Family member participants report experiencing complicated and on-going grief (Boss, 2010). Family members report being traumatised by the injury to their relative and that, unlike with bereavement, there are no recognised ceremonies to support notions of "closure" and so grief remains frozen and unresolved (Boss and Carnes, 2012, Roos, 2014). One participant, John's mother, did create her own ceremony many years post-injury by placing flowers at the site of her son's car crash. Participants with longer experience noted this lack of closure directly, acknowledging that theirs was a

continual and chronic process rather than a one-off event. This chronicity reflects the case for the brain-injured people themselves (Masel and DeWitt, 2010, Corrigan and Hammond, 2013), the relative's experience being driven by the often negative and unrelenting but often changing, experiences and functioning of the injured.

Participants were universally lacking in in-depth knowledge of ABI prior to being affected. Even participants who work in the field of health and social care and had experience of such systems and some pre-existing knowledge, were not equipped by this to cope better; their pre-existing knowledge of brain injury was an abstract rather than a personal and emotional experience. Wider community, family and professional lack of recognition or understanding of ABI acts to exacerbate the isolation felt by the relative (Linden and Boylan, 2010). Relatives frequently gave up seeking support from a wider community that would not or could not understand and fully conceptualise either the impact of the ABI or the secondary trauma suffered by the relative (Jordan and Linden, 2013). Unwelcome experience taught participants that the effort expended in explanation was not worthwhile. Where support was forthcoming from family, friends or neighbours it was very much appreciated. Such support was sometimes noted to be practical or financial; non-affected (or more distantly affected) individuals undertaking tasks such as driving, cooking or looking after children. Whatever the nature of the tasks undertaken, the appreciation of support provided would appear to be based upon the focus being directly upon the non-injured relative. This support was provided unquestioningly, being predicated upon an acceptance of practical or emotional need that did not require justification.

Unresolved grief, particularly when set in the context of the invisible but relentless and enduring nature of ABI, leads to ambivalent feelings by the relative who reports no option but to continue to provide support and remain involved (Boss, 2010, Collings, 2008). Participants were therefore simultaneously coping and not coping, loving and not loving, hoping and not hoping. Grief was unending, being managed and not managed, there was no linear process of restitution or acceptance. Conflicting thoughts and emotions occurred concurrently, losses were permanent and ongoing, incorporated into the present and the future, the past was dislocated. The experience

changed the participants; resilience and growth co-occurred with their opposites, this potentially contradictory state a reflection of the unclear and ambiguous position relatives were thrust into.

This paradoxical condition was well described by Simon's partner, a woman who had taken on funding authorities to secure her husband's specialist long-term placement. This battle with administrative staff, who she perceived as very rude, uncaring and lacking empathy, had drained her. She had felt abandoned by Simon's family, by many of their friends and all of his former work colleagues. She identified that she had grown as a consequence of the battles she had fought and by the fact that she was undertaking roles she had never attempted before. She professed that she could not go on, but she carried on and said she could not give up. She stated that her marriage vows were core values that she held dear and essential to her being, but she questioned whether she could keep them. Despite all of her work and her relentless commitment, she struggled with questions relating to the value of Simon's life, hesitatingly querying whether his survival had been the best outcome; she had palpably lost her sense of self and her identity and she was ashamed that she had thoughts about whether his death would have been preferable. The burden felt is perceived as wholly unavoidable, an inescapable duty undertaken out of a sense of love and a lack of alternatives.

Simon is placed in a specialist unit. She visits up to three times a week and takes the children. Other service users scream and swear, sometimes at her and her children, Tom and Evie; it is not an environment that she or the children had experienced before. One Christmas she visited and watched, with Simon, a pantomime put on for the residents; she described it as being a very poor production but her husband was delighted by it, clapping along and looking truly happy. She continued by describing a further visit with the couple's children:

A couple of weeks later the unit did a New Year's Eve party, they did it on the 30th, and it was 5 until half past 6, so the four --- the three of us went, and Tom and Evie did some dance demonstrations at the beginning, they had a DJ come

in and it was just lovely, and at that moment, the kids were like ... "it was great mum! We had a lovely time, oh thank you for taking us!" And it felt like yes, this is like our ... a separate family for us, all the staff, they love Tom and Evie anyway, and Simon, so that felt ... so you have got the two contrasts, one minute I just thought what am I doing here? And where the next time I just thought this is our life, and this is ... (Partner 04)

A New Year's Eve party held for 90 minutes at 5pm on the 30th December speaks volumes about Simon's disconnect from his former existence, as does his partner's mistaken and corrected statement that the family of four visited, when in fact only three travelled; Simon is a loved father and partner but he does not reside with them. Despite all of this, the event was considered to be wonderful, in sharp contrast to the visit a few weeks previously. Simon's partner recognised, during our conversation at least, that this was her life and it was one that was entirely separated from her other lives, the one outside of the unit and the one she had before her husband's brain was so devastatingly damaged. Hers is a life riven with contradictions and ambiguity, which take an inescapable emotional toll upon her. She reports feeling wholly lost, not knowing what to do or where she is. She has sought professional psychological support and reported that her counsellor appears lost too, not knowing what to say or do when there are no good outcomes and there is no end in sight.

The ambivalence felt by some participants could present in the extreme with some expressing love and hatred for the injured party, even wishing them alive and dead simultaneously (Webb, 1998). This ambivalence and the contradictions it fostered was noted by some participants who recognised their own fractured sense of holding paradoxical and incongruous views and emotions. Some held very difficult to verbalise views regarding the value of life and whether one's one child or partner may be better off dead (Higham and Phelps, 1998). This taboo subject is noted in other research to be felt but rarely expressed (O'Dwyer et al., 2015), though it is acted out by relatives of people with disabilities in a number of instances with tragic consequences (Brown, 2012, Barnes, 2015).

Information given to relatives at the point of injury is very variable and conflicting reports were given regarding the usefulness or otherwise of what was provided (verbal information and written material) whilst an inpatient/upon discharge. Most usually the information was either considered inaccurate (too pessimistic or too optimistic) or non-existent, when the brain injury was not mentioned or barely mentioned to some participants. Discharge from hospital is universally noted to be a particularly problematic time where a lack of information and follow-up support is reported to leave the relatives with little knowledge upon which to base on-going expectations (Abrahamson et al., 2016, Chaboyer et al., 2005). When ABI was mentioned, the functional impact of the injury, in a practical sense, was less commonly discussed. Participants who were given accurate if negative appraisals of likely outcome recognised the value in knowing this, in common with other difficult prognoses (Fallowfield et al., 2002); however the importance of hope, noted to be important for rehabilitation (Snyder et al., 2006), plays a part for relatives too when dealing with unknown, unknowable and uncertain outcomes (Kreutzer et al., 2010, Mattingly, 2010).

Respondents and participants noted that more information was required. Those that were satisfied that their information needs had been met had often needed to search for this themselves. Information from specialists, in particular the charity Headway, was useful, in line with studies of what support alleviates relatives' distress (Morris, 2001). Information has been found to be the need most regularly reported by relatives (Sinnakaruppan and Williams, 2001), with the need to be involved in health and care planning the second most reported (Kolakowsky-Hayner et al., 2001). In the related field of stroke rehabilitation and research, an absence of individualised information across domains has been identified as an issue for relatives (Wiles et al., 1998). Whilst stroke is a form of ABI, the aetiology and outcome will often differ. Stroke is more likely to create a focal and not global/diffuse injury, is less likely to involve the frontal lobe and age at point of injury tends to be higher (Feigin et al., 2010). Direct comparison may therefore not be entirely appropriate.

Hospital-based staff who are most likely to be the first possible source of information for relatives are experienced in acute care (by definition) and do not have an on-going

relationship with individuals and families. Their involvement and expertise is not concomitant with the long-term experience of family members. They deal instead with gross and acute changes to health and functioning (immediate risk to life, prevention of deterioration of clinical condition and hands-on care tasks), not the potentially more subtle and enduring changes that family encounter over the duration of the lifetime of the injured.

Injury-related factors, such as neuroimaging results, Glasgow Coma Scale ratings and Post Traumatic Amnesia, the presence of other injuries, early (post-injury) cognitive and behavioural difficulties, demographic factors - including age, gender, genetic status, education, pre-injury IQ and employment status - and social factors including family and other social support, cultural factors, pre-injury psychiatric history and coping style are all known to be implicated in outcome from severe ABI (Ponsford, 2013). These factors are noted to be interrelated in a complex manner and therefore are not amenable to simple prognostication. Neuropsychologists within neurorehabilitation settings, applying specifically designed neuro-psychometric tests, are noted to have limited empirical basis upon which to formulate assessments of functional abilities based on test results alone (Struchen et al., 2008, Manchester et al., 2004); medical and nursing staff in acute settings have fewer tools and even less relevant experience upon which to base opinions regarding outcome.

Long-term outcome following ABI is very unclear at the time it occurs and in the early acute stages. Long-term studies show both positive and negative changes in disability status over time (McMillan et al., 2012, Whitnall et al., 2006, Corrigan and Hammond, 2013). Psycho-social functioning is noted to deteriorate for some (Olver et al., 1996) and the timescales over which this is measured are lengthy and not immediate at point of injury, in particular when considering the impact of invisible difficulties such as executive impairment (Draper et al., 2007). Outcome measures, if applied at all, are frequently very blunt. The most regularly used, the Glasgow Outcome Scale Extended (GOSE), has 8 potential ratings for outcome, death and vegetative state being the lowest two (Wilson et al., 1998). The usefulness of the GOSE is questioned with

regards its relevance to the assessment of functional changes in the later stages (2 years plus) of ABI recovery (Sandhaug et al., 2015).

In a practical sense therefore, staff in acute settings may be aware and pass information to relatives regarding, for example, the possibility of memory impairment or personality changes. How these changes are felt by a relative (and the impact these changes have upon them), or how they functionally manifest, are the relative's concrete and reified experience of these abstract concepts. Relatives do not experience the impairment caused by damage to the brain of their loved ones; they experience the consequences of that impairment in terms of the changes the injury causes to behaviour, activities, personality and roles.

Participants who noted that they were provided with information that they deemed useful described being forewarned to prepare for a changed life, theirs and the injured party's, and of being informed of a range of domains that may suffer long-term impairment, including issues relating to behaviour, personality and functional abilities above and beyond reasons of physical impairment alone. Changes to behaviour, mood and quality of life are noted to be the factors that relatives request information about years after injury (Junqué et al., 1997). A number of participants noted that the information they were given in the acute setting was accurate but that they could only recognise this with the advantage of hindsight. At the time it was not meaningful or helpful; it was an abstraction of their likely future but not one that could be usefully conceptualized through provision of standardized and generic and non-person specific information.

Several participants noted that the most useful aspect of information that they were given during the acute phase of the injury could be characterised as being based upon the notion that their life and their injured relative's life was going to change and that this was inevitable. At this juncture uncertainty is possibly the only certainty and it is this that drives the ambiguity of the losses experienced.

This highlights a mismatch between the well-established needs of relatives for information - a prognosis, a guide to how best to help and knowledge of health and social care systems - (Serio et al., 1997) and the acute setting practitioner's capacity to meaningfully provide this. Whilst this is based in part in the acute setting practitioner's ability and knowledge, a more significant aspect is that the outcome is unknown and unknowable at this juncture. The information required is in fact knowledge of person-specific functioning across a range of domains and settings and over time. The information that can underpin this knowledge can only exist as an abstract at this point; the knowledge of actual functioning in situ, of the strategies, routines and structures that will limit or compensate for the impact of impairments, needs to be created iteratively over time. It does not and cannot exist, except as abstract, when more concrete knowledge is required. This is in conflict with the known need and wish of relatives to have information regarding prognosis (Lefebvre and Levert, 2012). The relative, at this juncture, lacks insight into their lack of knowledge, being unaware that the knowledge they need has to be created to be real, practical and useful for them.

Neuro-psychometric testing, where applied and unless integrated and led by in-situ knowledge and third-party information over time, serves as further abstraction. The relative, who knew and knows the injured pre and post-morbidly, is possibly the only involved individual who has concrete evidence of functional change. They are therefore potentially the best placed to understand the actual impact of the injury and so provide the information required by the professional to underpin their formulation (Clark-Wilson et al., 2014).

6.2: The shared if different experience of family members and people with ABI

Whilst there are clear differences in the type of trauma experienced by people with an ABI and their relatives, there is an undeniable truth in the assertion that the event can be very traumatic for both. The losses experienced by the brain-injured are wide-ranging and, unless the unlikely full and total restoration of function takes place, are based in the present and the future. Rates of relationship breakdown are noted to

increase (Wood and Yurdakul, 1997) with a deterioration in quality of relationship for those who remain together (Williams and Wood, 2013) and difficulties with sexual relationships identified (Oddy, 2001). These issues are experienced by both parties in the case of an injured spouse where increased responsibility for decision making (by the non-injured) is also adjudged as a burden (Knox et al., 2015) along with frequent reduction in family income owing to loss of employment (van Velzen et al., 2009). Difficulties parenting, as a consequence of the injury, have an impact upon a couple's children (Tiar and Dumas, 2015, Holloway and Tyrrell, 2016) and the uninjured parent accordingly (Uysal et al., 1998).

For parents of individuals with an ABI the losses they experience are of a different type and the relationship is based upon family connectedness and not pre-injury choice of partner. Age of the injured party at the time of injury has an impact upon how the non-injured parent experiences losses, with some parents taking back on caring (including physical care) roles more usually associated with infancy. Loss of expectations held by the parent participants was commented upon along with fears for a future following their anticipated pre-deceasing of their injured child (Knox et al., 2016).

Whilst the nature of the losses experienced by the injured and non-injured participants is therefore different, both parties experience losses that are unclear, ongoing and all pervading. A further similarity between the injured and the non-injured is the lack of choice both have once the injury has taken place. For the injured the process of recovery, rehabilitation and adjustment is clearly a personal one as experienced; for the relative the lack of choice, as expressed by participants, is one where they can neither be unaffected emotionally nor withdraw from providing the support they do. The unavoidability of involvement of the participants (a probable inherent sample bias here, uninvolved individuals are unlikely to have responded to the request for study participants) is based, in part, upon the lack of alternatives and their implicit knowledge of what will happen without their input in terms of deterioration of functioning and loss of connection to society/family structures. These anxieties are borne out by the literature regarding psycho-social deterioration, reduced quality of life and increased rates of co-morbidity, suicide, homelessness, incarceration and

premature mortality (Corrigan and Deutschle, 2008, Jacobsson et al., 2010, Simpson and Tate, 2007, Oddy et al., 2012b, Pitman et al., 2013, McMillan et al., 2012, Corrigan and Hammond, 2013). The relative's inability to "let go" is underpinned and substantiated by what happens to some people with an ABI if they become detached from formal and informal care networks.

Furthermore the loss of self or identity that is experienced by brain-injured people (Gracey and Ownsworth, 2012, Gracey et al., 2008, Martin et al., 2014) is experienced, albeit differently, by participants too as a direct impact of losses experienced but also as a consequence of threats and changes to their assumptive world (Kauffman, 2002, Cann et al., 2010). The absence of understanding from the wider community and the invisibility of ABI, both in terms of symptoms/behaviour but also in an absence of realistic representation in mass media, serves to exacerbate this loss (Linden and Boylan, 2010). The survey used in this research identified a significant statistical correlation between increased difficulties with behaviour and loss of insight and reduced friendships for the non-injured party. Many participants had few if any contacts or experience of others, directly or otherwise, that had similar experiences. Those that had encountered peer support, often via the charity Headway or from the family support provided by specialist services, frequently described this as useful, partly as a means to gain information and knowledge and partly to aid their understanding that they were not alone in experiencing such difficulties.

Participants therefore describe trauma, losses, complex grief, loss of an assumptive world, a lack of choice regarding the position they find themselves in, a need for information and clarity (specific knowledge) but at best being provided with generic and possibly abstract information. In this sense their position mirrors that of people with an ABI who struggle with insight following their injury. Information in and of itself, even if understood, recognised and wholly accepted is not comparable to insight; it equates to an intellectual awareness only (Crosson et al., 1989). This intellectual awareness, for some, can develop into increased insight over time if feedback from real-world performance can be integrated with knowledge held to help create a more accurate and reliably predictive understanding of ability. For many people with a

severe brain injury this may never occur as a consequence of the very metacognitive and executive impairments that preclude such learning from environmental feedback with the concomitant need to generalize this learning across time and setting (Prigatano, 2008). Individuals' decision-making skills may remain affected in function, notwithstanding what is said in formal assessment or other settings (Lennard, 2016, Acquired Brain Injury and Mental Capacity Act Interest Group, 2014).

Relatives of people with a brain injury are not likely to have such metacognitive damage and so are better placed to integrate experience and information to create knowledge that can be utilised to explain the presentation and behaviour of the injured party. This acts to support accurate prediction of likely future need/behaviour. In doing so relatives can move from ignorance of brain injury to a position of intellectual awareness (when they possess abstract information only) through to anticipatory awareness when their knowledge is reinforced by experience in situ of actual functioning. Such a process is not without difficulty or emotional cost. Creating, comprehending, accepting and incorporating knowledge into one's understanding of a loved one, particularly when the knowledge is unwelcome, is not straightforward. Academics from a range of backgrounds continue to work to understand even the uninjured brain (Rose and Abi-Rached, 2013) and how it functions. Academic and professional interest in ABI is a relatively new phenomenon caused in part at least by previous high rates of mortality at the time of injury, survival rates have improved (Powell, 1997). Relatives are therefore endeavouring to learn a subject that is both complex and unclear, while doing so in an emotional/familial context.

This absence of certainty places both people with a brain injury and their relatives in a liminal space where clarity is absent. As noted for cancer patients and their relatives, the acute phase of this liminality is marked by "*disorientation, a sense of loss and of loss of control, and a sense of uncertainty*" (Little et al., 1998, p.1485). Later as the situation moves from the acute to chronic phases, liminality may be experienced as a transitional phase, potentially a perpetual one, where individuals attempt to create meaning by means of narrative (Little et al., 1998, Sabo, 2014). The "borderlands" (Mattingly, 2010) that relatives find themselves placed within are spaces that they

previously did not encounter and where individuals attempt to create meaning, with hope, in changed circumstances. As interviewees described, they are forced into unfamiliar clinical and medical cultures where there may be no common language or understanding. Simultaneously they may be forced (or drift) out of spaces and cultures that helped shape the pre-injury time phase, such as friendships, work and a sense of familiarity with the world.

In some instances the relatives need to take emotionally weighty decisions regarding the lives of the injured (Brown, 2011), that confront moral and ethical dilemmas as well as existential issues regarding the meaning of the self (Mwaria, 1990). Questions as to whether to remain in a relationship with an altered person, whether to continue living in the same accommodation, how much contact and how much control the relative will exercise are taxing dilemmas to be faced. Switching off life support or withdrawing artificial hydration and nutrition are ethical and moral decisions of the highest possible order (Kitzinger and Kitzinger, 2015, Fins, 2015a, 2006).

The relative's experience, as described by participants and respondents, is therefore a transformative one, a temporal journey where rehabilitation and restoration of functioning are keenly held goals to work towards. Unwelcome adaptation to changed reality is a likely consequence too, as is an on-going sense of loss and lack of clarity: a potentially unending dissonance. Relatives report that this process is either supported or disrupted by the responses they receive from professional services and the wider community.

This transformative journey is set in the context of the seven themes identified in this research. When looking at what relatives say works for them, what facilitates positive change and growth following and during the on-going unending trauma of ABI, an approach or style of input became identifiable. Relatives described a need for interventions that were greater than simply the provision of information or even an empathetic approach, valued though these were. The most valued staff or services acted as "expert companions", combining their pre-existing specialist knowledge with the involved relative's knowledge and experience (Calhoun and Tedeschi, 2006). Such

input is noted to support the development of the “new reality,” a method of upholding the relative’s creation of an updated (neuro) narrative that reflects their situation in all of its complexity, a nuanced rather than simplistic approach.

6.3: The role of the “Expert Companion” for the relative’s transformative journey

Do not walk in front of me - I may not follow

Do not walk behind me - I may not lead

Walk beside me and be my friend.

(of uncertain attribution)

Despite the real challenges, participants were able to continue to support their relatives and to make meaning out of their experience (Park and Ai, 2006). The ambiguous nature of the losses experienced prevents a more straightforward application of the notions of recovery or even posttraumatic growth, for there is no fixed point from which to grow as the losses are continuous, develop over time and are unclear, potentially perpetually so. However Calhoun and Tedeschi’s model of how to support growth following trauma is echoed by the participants’ experience of what was found beneficial (Calhoun and Tedeschi, 2006a). In this model, trauma has been experienced, the traumatised individual needs support to make sense of this and this is noted as a process of exploration to achieve a “new-normal”, a way of using structured and skilled support to integrate the traumatic experience, understand it and contend with it. The relatives’ experience as described in the themes is however not wholly co-terminous with Calahoun and Tedeschi’s work which tends to focus on single fixed traumatic events (such as an individual being present during an event like a hurricane or tsunami) or an unexpected bereavement. The nature the ambiguity of the losses suffered by relatives and the lack of community understanding of the experience serves to isolate the relative and provide no clear and straightforward path to solution. Their experience of trauma is also secondary, they are affected by the trauma that has occurred to their relative.

However, participants' sense of what worked for them resonated with my understanding of the concept of the "expert companion", a humanising co-traveller on a transformative journey to discover a new reality and seek to accommodate (even if not to accept or adjust to) life post-ABI (Calhoun and Tedeschi, 2012). Participants' descriptions of services or informal support that they found beneficial mapped on to my understanding of how the expert companion works (Calhoun et al, 2010). In this model grief is recognised to not be a linear process, the professional offers humility, respect and constancy and refrains from platitudes. The expert companion is able to tolerate, recognise and name ambiguity and has the courage to hear what is likely very difficult to hear, paradoxes about the grieving relatives' view on the value of life or death being one of these. Such an approach was reflected within the data and themes developed in the inductive stage of this research and the challenges I identified speaks to this aspect of the expert companion's approach.

The expert companion, in line with Todres et al's descriptions of what humanises health and social care, aims to avoid dislocating individuals from their reality, making them passive in the process, and instead recognises the individuality not homogeneity of affected parties. In doing so this approach promotes meaning-making, creates a sense of agency, acknowledges uniqueness and supports the notion of travel and of process (Todres et al., 2009). Such an approach supports the clinician/professional to reject pathologising attitudes towards those in deep distress who may react poorly to input (Kitzinger and Kitzinger, 2014a), enabling a sense of closeness to be developed (Todres et al., 2014) so that distressed individuals who may be unable to positively affect outcome are supported to feel more empowered nonetheless (Lundqvist et al., 2002). Recognition of the need to explicitly understand the ambiguity of loss felt, and work within and upon this, is noted as required to promote emotional recovery (Kreutzer et al., 2016).

At its simplest the expert companion supports the development of a "new narrative", the development of a new story of life, and in doing so validates experiences and reconnects individuals with their strengths and previously held values (Butera-Prinzi et al., 2014). To do so the practitioner, acting as an expert companion, needs to develop a

genuine relationship with the traumatised individual, to learn about their life prior to the event that divides it into a “before” and “after”. This provides opportunities for a narrative reconstruction that includes and values the past as a component of the present (Neimeyer, 2001). This relationship forms the basis of the development of the “wisdom” required by the survivors of trauma and is a creative process, as the expert companion does not start upon this journey knowing the end-point.

The expert companion cannot lead the survivor toward wisdom because this is a creative process. Indeed the expert companion recognizes his or her own limitations and is open to changing, learning from the survivor. Clinicians who see themselves as expert companions practice this humility with trauma survivors, because it is all that is really possible under difficult circumstances that have no ready answers (Calhoun and Tedeschi, 2006b, p. 308).

Such an approach may be relevant and found effective by relatives owing to the need to respond to the complex changes in role experienced. The nominal roles of “father”, “partner” or “daughter” etc. remain the same but the content of that role, the intrinsically held expectations of it, change in an instant upon ABI. The previously accepted (internally and externally) “story” of the role is rendered obsolete but not in a fixed and finite way, the outcome is unknowable at commencement; the functional impact of ABI, how it is experienced by the injured and non-injured parties, becomes established over time. The invisibility of some difficulties experienced and a lack of knowledge of the condition by family, by professionals and by the wider community affects how this is understood. A family’s complex pre-ABI narratives are therefore dynamically and unknowably altered outside of any formally understood context, whilst the role/label remains unchanged.

Respondents to the survey identified a marked difference in their ratings of brain injury case managers (BICM) compared to social workers, the former being the highest rated service with the smallest standard deviation in the scores provided and the latter being the lowest. Participants likewise relayed generally far more positive experience of the input of BICMs compared to social workers. However, the sometimes very

negative appraisal of social workers was counter-balanced in part by positive stories regarding perceived humanity and constructive alliances formed with a few, outcome being less key than process. Understanding that the relative is a survivor of trauma and that recovery from such traumatic experiences is a process may explain the difference between those professionals that are rated highly and those that are not. Similarly the recognition that there may be no “map” is a useful starting point; continuing this metaphor may suggest that possession of a compass is however a pre-requisite for an expert companion, supporting the direction of travel if not pre-defining the destination or duration of journey.

The BICM’s role has been positively reported upon and identified as required in cases of prolonged disorders of consciousness (Kitzinger and Kitzinger, 2014b), for community reintegration (Abrahamson et al., 2016) and for those with complex conditions, ABI included (Gridley, 2013). The BICM should have expertise (knowledge of ABI) but applies it in a bespoke manner, recognising that the relative is firstly also affected but secondly is integral to the process of rehabilitation/adaptation (Yeates, 2007, BABICM, 2016), and that ABI is a lifetime process not an event (Masel and DeWitt, 2010, Clark-Wilson and Holloway, 2015), is perhaps what defines the difference between the BICM approach and that more typically found in generic adult social work. Social work with adults, increasingly reliant upon care management approaches (Lymbery, 1998, Dustin, 2007), short-term in nature, ‘brokering’ packages of care (Leece and Peace, 2010), working mostly or only with the affected party, often dogmatically presupposing client/family expertise and that insight into the condition exists, is in absolute conflict with the needs of brain-injured families. Families affected by brain injury are usually in wholly uncharted territory, lacking knowledge and experience of the condition and its likely impact, particularly in the earlier stages. Work practices that take no account of this lack of knowledge and assume insight and expertise on the part of the family member and the injured person are commencing from a fallacious starting point (Abrahamson et al., 2016). Such practices are an approach more likely to fail as they are neither underpinned by an understanding of the bio-psycho-social nature of the condition nor are they cognisant of the emotional and social impact upon relatives (Williams and Evans, 2003, Serio, 1997). Interventions

that are not focused upon potential for change and informed by rehabilitative knowledge negate its possibility. This approach fails to support transformation or travel towards it, and cannot do so owing to a lack of expertise or development of a relationship that supports the co-creation of new knowledge. In doing so harm is potentially reinforced, narrative becomes stuck and family and professionals are not integrated. Not uncovering or understanding the causal mechanisms that lead to the relatives' experience being as it is, from a critical realist perspective, negates to understand how the context of the situation is part of its explanation (Pawson and Tilley, 1997).

In contrast to this, the expert companion practises in a way to develop knowledge, to help develop the new "neuro-narrative". The whole story is affected by neurological changes and so the content of the relative's role has to include this. The expert companion provides a context, a space and a sense of continuity to facilitate this. The relationship element of this cannot be over-stated; participants identified that the people that made the most difference were the ones who went beyond what they had expected, who gave sufficient time and paced their work and who saw the ABI in a wider (bio-psycho-social) context, providing knowledge, practical and emotional support. Doing this helped normalise the experience. Relatives described someone with whom they had a relationship. Whilst the ABI is often the focus, for obvious reasons, it is setting this into the relative's broader context that enables narrative co-creation to incorporate but not be swamped by it.

The expert companion cannot "make things better", to undo the damage unleashed by an ABI. The approach that relatives' value is one that enables ambiguity and ambivalence to be named and defined as normal. It is one that supports relatives' sense of hope and shapes learning as a shared endeavour. The expert companion offers to stand with the relative and 'gaze into the glare' of their grief to 'help minimise its terrible isolation' *Adapted from* (Charon, 2012, p. 346).

Table 20 provides a summary of the characteristics of professionals and of services that relatives described as helpful or unhelpful for them in relation to their learning

and in relation to supporting the person with an ABI. An expert companion, irrespective of their formal role in the process, by definition acts in accordance with those characteristics that are defined as helpful. It is the unique nature of ABI that defines what is perceived as helpful; other conditions or situations may have differing positive/negative characteristics. In particular the impact of loss of insight and dysexecutive functioning shapes the response required, as does the ambiguity of the loss and ongoing grief suffered by the relative.

Table 20: Characteristics of helpful v non-helpful approaches

Approaches that do not help are characterised by:	Approaches that help are characterised by:
Lacking in expertise about ABI AND is perceived to not care about the individual or their family. Does not demonstrate humanity and empathy.	Has <i>or</i> lacks expertise about ABI but is perceived to care about the individual and their family. Demonstrates humanity and empathy.
Places primacy of role unilaterally with the injured party.	Shares primacy of role with injured party and with family.
Short-term assessment style intervention, care management or rigid boundaries of provision.	Longer-term, iterative assessment, life-care planning, flexible boundaries to provision.
Uniform provision.	Bespoke provision.
Client is unquestioningly believed to be knowledgeable about their needs and what services are required OR the professional is perceived to believe that they know all that is relevant to know and this boundaries their involvement and service provision.	Client and family have valuable information and views but these are unlikely to be fully informed about the nature of ABI. The information required by family does not initially exist and needs to be co-created. The professional acknowledges that they do not have all of the answers but is not limited by this, instead this drives their input.
Client expertise and view has primacy over decisions taken regarding service provision.	Client and family expertise and views drive the process of rehabilitation and change but are augmented by the expertise and input of others. Discrepancy between professional, client and family view is an opportunity for exploration, progress and greater understanding by all parties.
Involvement is short-term in nature, potentially a one-off visit, the situation is defined and definable.	Involvement may be long-term and is a (therapeutic) relationship. Understanding of and by the individuals and family will develop over time as functional abilities/difficulties are encountered and this information integrated in the understanding of the situation. Situation is dynamic, changeable and not easily defined.
Input is defined by eligibility criteria and by the structures and rules that govern the service provider to boundary the intervention.	Input is defined by need, informed by flexibility and necessity, responding outside of organisational boundaries.
Input is reactive, a snapshot, focussed on the immediate and current presentation.	Input is proactive, a process, incorporating knowledge from pre-ABI time, whilst recognising that the future is something that may be constructively shaped.

The practitioner working as an expert companion undertakes a style of work therefore that is suited to ABI's nature as a "family condition". Brain injury case managers are noted to be clinically and financially beneficial in complex cases with co-morbidities (Heinemann et al., 2004, Ashley, 2010). Brain injury case management, usually from the independent sector, is noted to support and improve discharge planning and outcomes (Hammond et al., 2012) and demonstrates complex knowledge and nuanced skills (Sullivan and Floyd, 2012). Severity of injury, behavioural difficulties, executive impairment and loss of insight are noted to be linked to level of case management service use (Arnold and Elder, 2013, Clark-Wilson et al., 2016). A case management approach is identified as an effective long-term approach across an individual's lifespan (Clark-Wilson and Holloway, 2015). Such services are identified as valuable at time of discharge and for those with family with prolonged disorders of consciousness (Kitzinger and Kitzinger, 2014b, Abrahamson et al., 2016).

Social work, particularly with adults, by contrast is less likely to have the knowledge, approach or style of practice that is in alignment with the needs of families affected by brain injury. In the interviews, respected social workers were notably those who were reported to make a personal connection, to form the relationship, the first and necessary role of the expert companion, even if they were unable to effect change. Skilled social workers were recognised as bearing witness to the family member's grief (Konrad, 2009) but when the losses experienced are unclear, ongoing and varying, more is required to create change and prevent the experience of grief being so isolating. Those services more regularly highly rated undertook to form such relationships and had underpinning knowledge, an approach and a style of practice that supported change, integrated the family member and were structured and guided by the response needed to the condition. Expert companions offered to "stand" with the traumatised as they experienced complex grief (Charon, 2012). In doing so the expert companion 'translates' abstract notions to more concrete realities, a context is created within which a relative may begin the unending process of reconstruction, their own form of neurorehabilitation.

Previous research and literature, the vast majority of which is outside of the field of social work, has identified the nature of ABI for the affected individual, rehabilitative and other interventions that may benefit recovery and adaptation to changed circumstances, and the impact that this has upon families. The key points of this study are to integrate this knowledge with a greater understanding of the relative's experience, over extended time periods, and to develop the notion of the use of the 'expert companion' to facilitate the co-creation of a new narrative by which the relative can better live. By eliciting and using the experience of relatives to ask "what is your experience and what works?" it has been possible to ascertain that the assistance and wisdom required by relatives has to be (individually) constructed. Services and/or individual professionals or informal supporters can aid or hinder this process. It is the unique nature of the specific and enduring grief, the ambiguous losses experienced and the ambivalence that ABI creates, in conjunction with the highly complicated nature of ABI, that leads to the type of response found to be most supportive. Professionals working as expert companions integrate knowledge of the themes that are found in this study into their approach and are truly valued by people who are motivated to do their best for their loved ones.

The values and skills that underpin social work are commensurate with the needs of people with an ABI and their families. The current knowledge base and structures under which social workers labour do not easily facilitate enabling the profession to develop expertise or practise companionably. This is in sharp contrast to those professions or services that do work this way, the services and individuals who are noted to make a difference to lives that have been irrevocably altered. Valued individuals play a part in generating a new narrative by understanding the ambiguous nature of the grief experienced, recognising that this is key to the relative's experience.

6.4: Limitations of this Study

As noted in chapter 3, there are recognised limitations in the method I used for recruitment and in the type of analysis, not least of which is researcher bias. As a solo rather than a team endeavour, these biases have a greater chance to evade scrutiny and remain unchallenged.

A limited number of men replied to the survey. The method of choosing participants from the respondents intentionally excluded gender as a criterion; choices were made blind to age, gender, relationship status, geography, etc. This culminated in a participant list that included only one male. Sexual orientation and ethnicity were not identified by the survey and hence differences between groups could not be identified in this research. Representativeness is therefore questionable and would require a more targeted piece of work to ascertain. Relatives of individuals who suffered mild to moderate brain injuries or those who made very good recoveries are not represented.

From a positivist perspective, direct generalisability to the wider population of work with a strong qualitative component and limited sample size is clearly highly questionable; from a critical realist perspective, the very prospect of direct generalisability betrays over-confidence about the relative unimportance of contexts. The notion that the data gained from this study has a degree of broader relevance relies instead on theoretical generalizability (Sim, 1998). The method of data collection and analysis has undoubtedly shaped its findings. A researcher with no brain injury knowledge or experience may have elicited completely different information, a bias potentially inherent with professional/near insider research. Another form of analysis may have identified different conclusions.

Criticisms of the representativeness and generalisability of this work are therefore wholly accepted. The safeguards put in place to limit these, which include the role of skilled academic supervisor, are not sufficient to counter these valid critiques. Instead I would argue that the research has a sense of plausibility and applicability (Marchal et al., 2013, Greenhalgh, 2016, Noble and Smith, 2015). It is based upon the stories of 110

people, stories that are usually hidden. Whilst my prior experience was reflected in the stories told, parts of this stood out as being different, in particular in the case of questioning the validity of the life lived by the survivor, and in my growing realisation of how family members created new and cogent narratives and what supported them to do so.

A wholly different design using tools considered valid may instead have supported research that enabled predictions in this population about the frequency of particular outcomes, such as rates of depression amongst female partners of men with a severe brain injury for example. However, focusing upon the narratives of the affected parties enables sense to be made of this experience. Importantly I believe that this approach, valuing the relative's perception of their experience, enables the development of a more cogent description of what the relatives state they need. Knowing what percentage of female partners of men with severe brain injury experience depression may be useful, but it tells us little of why they experience depression, how that depression is experienced, how those women differ from similar women that do not experience depression and what approach services can take to alleviate this meaningfully. In this sense I would defend the method used as being one that, by valuing narrative, facilitates the development of its description and does so with a richness that enables a genuine verisimilitude to be established.

During the analysis phase of my research I presented my findings at international and national conferences and at small Headway groups. I have therefore spoken to both professionals and relative survivors who did not take part in the research. A lack of contradiction by any party (and instead a recognition that this reflected their experience) cannot stand as universal validation of my findings but it has supported me to consider that I may not be wholly mistaken at least.

6.5 Recommendations for Practice

In the twenty-five plus years since I commenced working with people with an ABI there has been great progress, most especially but not exclusively at the acute stages of injury. Interventions have developed that save lives that would simply otherwise have been lost, rehabilitation approaches and techniques (for those who can access them) can improve the lives that have been saved. A number of the people I work with who live a valuable and purposeful (if very different) existence, would not have done so without this progress. However the sheer lack of awareness of ABI amongst practitioners in many fields is something that has yet to be addressed. It was as recently as July 2016 that the British Journal of Social Work recognised in an editorial that ABI was a condition that sat firmly within the remit of the profession (Golightley and Holloway, 2016). This was preceded only a few months earlier by the publication of a joint Brain Injury Social Work Group and British Association of Social Work guidance document (BISWG and BASW, 2016).

For families with an ABI (or for the benefit of those yet to experience their ABI) this progress may be considered welcome but slow. ABI specific lobbying and interest groups, charities and individuals play a significant part in raising awareness of the condition but it is yet, to my knowledge, to form a specific part of the training of many professions, my own included. Knowledge of the impact of executive impairment and loss of insight upon assessment is central and key to that assessment not peripheral or optional. Until such education is introduced at University level and specific knowledge of the condition, its outcome and impact upon family is integrated in the training of all social workers, harm caused by the profession will be perpetuated and the ignorant tail will continue to wag the support-requiring dog. The themes described in this research identify that a lack of knowledge of the condition and a lack of understanding, in particular, of the impact of invisible impairments is key to the relative's negative experience of services. The failure of services to integrate this knowledge into their actions serves to reinforce the ambiguous loss and grief felt by relatives and distances

parties who may, in other circumstances, be supported to work together more effectively.

With regards to service provision, the individual practitioner with increased knowledge of ABI will be powerless to act until a level of flexibility in organisational systems is allowed for. People with an ABI do not easily fit care management models and so the best-informed practitioners cannot put their knowledge effectively into practice. ABI is a condition that challenges dogmatic, naively held beliefs about service user expertise and is poorly served by structures that require the impaired party/family to proactively self-advocate for services. Increasing use of notions of Personalisation does provide the opportunity for this to be challenged, to create bespoke responses to unique situations but the role of the social worker here is potentially as an equal and involved party, not as a passive and very transient broker. Responsibility for idea generation, planning, decision-making, reasoning, initiation of action and problem solving cannot be wholly delegated to those for whom these are their impairments, this is axiomatic. A failure to recognise these impairments, a wilful or accidental lack of identification of the bio-psycho-social nature of the condition, may lay behind rates of incarceration, homelessness, suicide, mental ill health and premature mortality amongst people with an ABI. Emancipation and true community integration is not achieved by failing to recognise the impact of significant impairments.

The Care Act 2014 provides the opportunity, if adequately utilised, to ensure that family are integrated into assessment and planning, it also allows for advocacy. Without underpinning knowledge of the condition and the impact this has upon the person with the ABI and their relative, without the integration of this knowledge into plans made and services constructed, this is likely to have little effect.

Condition-specific knowledge is clearly an advantage when dealing with issues as complex as ABI, one that was welcomed by participants and respondents. However

knowledge alone was not adequate; it is the relationship that professionals have with family and the person with an ABI that is also recognised above all as key. It possibly takes confidence and humility to practice alongside people, recognising one's own short-comings, lack of knowledge and fallibility, but it is this that is commented upon and valued. The expert companion may have expertise but it is the manner in which this is conveyed that defines whether or not it is effective.

Family members' lives are inextricably linked. Individuals did not exist as fully autonomous beings prior to the ABI; they do even less so following it. Therefore the genuine integration of family member knowledge and experience, working with family to facilitate and enable constructive change for all parties, is part of the professional role; that it may be a complicating factor and that such relationships may be marked by confrontation at points, does not preclude this. Better awareness by practitioners of both the impact of the injury on the individual and the complex nature of the unending grief this provokes may enable this relationship to be one based upon increasing trust and mutual learning rather than its opposite.

When I commenced my professional doctorate there were only ten academic articles published by UK social workers regarding ABI; there are now at least sixteen. There had never been an article in the *British Journal of Social Work* relating to working with people with an ABI; the editorial of the Journal had never previously recognised ABI as an issue key to the social work endeavour; there was no BASW validated guidance regarding the assessment of ABI; there was no ABI and Mental Capacity Act interest group; and the international journal *Social Work in Rehabilitation and Disability* had never had a special edition dedicated to social work and ABI. Each of these things has changed and I am pleased to have played a small part in this.

Nobody who completed the online survey or who kindly agreed to be interviewed by me had, prior to their relative's ABI, thought that this would be an issue that would

affect them. Their wisdom was hard earned and, I hope, can be used to support those families for whom brain injury is an as yet unimagined and unimaginable future. For this to occur social workers require a greater knowledge of ABI, its impact upon individuals and families and need to work in environments that promote the development of relationships between parties.

Chapter 7: Conclusion

"We must free ourselves of the hope that the sea will ever rest. We must learn to sail in high winds." — Aristotle Onassis

As with other research into the impact of ABI upon individuals and relatives, the results of this study demonstrate its severe and enduring nature. Despite the heterogeneity of the respondents and participants and the widely varying information provided and stories told, recurring themes were identifiable.

Severe brain injury happens to an individual within a family/community system, one that has pre-existing strengths, experiences, difficulties, relationships and responsibilities. The established family narrative – the past, with its assumptions, hopes and beliefs – is fractured from the present and future. The system changes over time, both as a direct and indirect consequence of the injury and irrespective of it. These changes can be experienced as wholly devastating or very subtle. Invisible changes to cognition, executive skills, behaviour and emotion, often in the context of loss of insight by the brain-injured person and a significant change to personality, are noted to be more keenly felt by relatives than physical impairment alone.

Participants/respondents report a lack of clarity and understanding in the early stages in particular, with an absence of information regarding how life will proceed for all members of the system. Even when well supported, professionally and informally, the changes and demands made upon relatives are experienced as a significant and unavoidable burden, emotionally challenging and affecting sense of self and social identity.

Formal and informal support structures are noted to vary considerably in effectiveness. A lack of follow-up service is regularly reported with little continuity, lack of adequate rehabilitation and/or community rehabilitation and support at a time when post-injury patterns of behaviour and belief systems are becoming established and are potentially amenable to positive change, malleable to effective input.

The family, not just an individual, is badly damaged and both the injured party and the relative can begin to become more isolated. The involved relative becomes responsible for a very wide range of issues including the “past”, “present” and “future” of the family story, a story that, post-ABI, is turned into a neuro-narrative. The response of non-specialist services can exacerbate this damage as knowledge of the impact of ABI upon individuals and families is absent and work practices do not take account of specific need.

The very nature of ABI is such that prognosis is not clear, as it develops slowly and is created as a function of injury and of rehabilitation, support, social setting and pre-morbid factors. There is no neuropsychometric test that can be applied at a point post-coma that will generate a clear and unambiguous picture of the future. At the most such tests may be indicative of likely impairments but not how these impairments functionally present at any point one, two or twenty years hence. The knowledge relatives need does not exist at point of discharge from intensive care/hospital and so cannot be “given” to the family member (in totality), even if it could be accepted and/or understood, as information that is not person or situation specific can only be an abstract. This abstract information requires translation to a concrete reality to aid future predictive thinking, planning, acceptance and accommodation of changes. This “translation” is an iterative process of observation, assessment, learning and adjustment to create the person and situation specific knowledge that is required to support both the brain-injured party and their relatives.

The post-acute services that relatives value are based within the range of statutory, private and voluntary sectors, most notably independent brain injury case managers, consultant clinical neuropsychologists and the charity Headway. Those that relatives are most critical of are those that do not take account of individual and family needs, lack specific knowledge of ABI, do not recognise the perpetual sense of unclear loss and do not support adaptation and adjustment to the relative’s unwelcome reality. Such services fail to facilitate and strengthen the creation of new and changed (but

valued) positive social identities. Such services do not see invisible difficulties and so do not address their impact in their work, failing to integrate the knowledge of the underpinning impairments that are the drivers to change and difficulty. Such services do not see the family member as client too, affected and now with increased responsibilities. They do not promote change over time or the telling of a new story.

The family member is in position of enforced responsibility, lacking information which is needed and wanted. He or she is set in a wider system that itself does not actually have that knowledge or information. Family are potentially more knowledgeable than professionals, in particular about pre-accident functioning and coping style. They are the curators of the past and managers of the present, but are not always effectively included in service planning or provision for the future. Adequate professional services are not always available, professionals regularly lack relevant knowledge, and are unable to support/affect change or are positioned in structures that are not established to take account of the reality of ABI.

The question for providers of services may be to ask how a relative alone, sitting in a damaged system, in grief and suffering ambiguous loss, can undertake the process of incorporating unwelcome and abstract information about invisible and difficult-to-conceptualise changes to support their own adaptation and acceptance, as well as promoting rehabilitation and positive change for the injured person? If family are to be responsible for undertaking a significant role with their injured relative, potentially for a lifetime, what supports them to do this more effectively for both their own wellbeing and that of the injured party?

What participants and respondents reported, what the literature states and what experience highlights is that the “knowledge” desired by relatives is something that needs to be created but that neither the relative nor the committed, available and knowledgeable professional own or possess all of this in advance. The knowledge needed for the relatives’ own transformative journey of healing needs to be co-created to support the development of a new and valued sense of narrative. This in

turn can support the generation of a new and altered but coherent social identity, which assists in living more successfully.

The valued professional does not take away the burden in its entirety or remove the ambivalence created by ambiguous losses. Relatives state, directly and indirectly, that what they value is a fellow traveller with expertise, who accompanies them through the liminal spaces that brain injury brings, and helps to explore new truths. These truths are created together with the express intent of not simply improving the lives of the injured and their family but of identifying and naming those lives, giving them value by valuing them. This process takes place by the humane co-generation of new narratives, the simple act of fitting words to a new life. This simple act is so complicated that it takes a lifetime and yet remains unfinished. This journey takes place in the perpetual borderlands of human existence where hope drives the motivation for the relentless love felt and expressed in the face of potentially incomprehensible grief, pain and loss, and even hate. The relative learns about themselves and their situation via the construction of this narrative, learning by speaking. It is the “telling” of the story that allows the potential for healing to begin (Charon, 2006, p. 65 - 67).

The alternative for professionals, to not act as such an expert companion on a journey nor to reframe and name the world with the relative, is to act in a manner that sustains or even exacerbates the damage caused by fractured narratives. Services that do not act in accordance with the needs of the injured and their relatives become deafened to their demands, shift blame to family or the injured and externalise responsibility for failure to progress or inability to accept or adjust to the new and unwelcome reality. The fault is seen to lie with the Other.

An expert companion, by contrast, co-produces a future that is more tenable and rejects notions of Othering. The expert companion moves themselves out of the potentially conflict-laden binary that Othering brings and supports belonging and integration instead. The pacing and the content of each journey will vary according to individual need and ability. Unvarying however is the underlying process of travelling

in hope towards the creation of a new and valued self, formed by the story of new-self. Such journeys are potentially perilous for both parties. The relative, already threatened by a frozen grief and by ambivalence and uncertainty, is supported and encouraged to set sail without map or compass, with no concept of the destination and no way back; the home-port no longer exists and cannot be rebuilt. The expert companion joins the voyage in a storm knowing that there potentially is no destination but the journey itself and that the map is forged along the route, forged in and by adversity. The map made is a narrative, it is an identity created by that narrative. The travellers become the truths that they tell themselves and each other on a journey that is without end.

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APPENDIX 1: Abbreviations

ABI: Acquired Brain Injury

ADL's: Activities of Daily Living

BABICM: British Association of Brain Injury Case Managers

BICM: Brain Injury Case Manager

BIRT: Brain Injury Rehabilitation Trust

BISWG: Brain Injury Social Work Group

CBIT: Child Brain Injury Trust

GOSE: Glasgow Outcome Scale Extended

IBIA: International Brain Injury Association

INSWABI: International Social Work and Acquired Brain Injury group

ITA: Inductive Thematic Analysis

ITU: Intensive Treatment Unit (sometimes referred to as **ICU** Intensive Care Unit)

MCS: Minimally Conscious State

NIHRSSCR: National Institute for Health Research School of Social Care Research

MDT: Multi-Disciplinary Team

PTA: Post Traumatic Amnesia

PVS: Persistent Vegetative State

PwBI: Person with a brain injury

RTA: Road Traffic Accident

UKABIF: United Kingdom Acquired Brain Injury Forum

APPENDIX 2: Ethics Approval

University of Sussex

Certificate of Approval**Reference Number:** ER/MH373/1**Title Of Project:** Acquired Brain Injury: the lived experience of relatives and friends.**Principal Investigator (PI):** Mark Holloway**Student:** Mark Holloway**Collaborators:** Supervisors - Orr/Watters.**Duration Of Approval:** n/a**Expected Start Date:** 01-May-2014**Date Of Approval:** 14-Apr-2014**Approval Expiry Date:** 01-May-2015**Approved By:** Jayne Paulin**Name of Authorised Signatory:** Stephen Shute**Date:** 23-Apr-2014

*NB. If the actual project start date is delayed beyond 12 months of the expected start date, this Certificate of Approval will lapse and the project will need to be reviewed again to take account of changed circumstances such as legislation, sponsor requirements and University procedures.

Please note and follow the requirements for approved submissions:

Amendments to protocol * Any changes or amendments to approved protocols must be submitted to the C-REC for authorisation prior to implementation.

Feedback regarding the status and conduct of approved projects * Any incidents with ethical implications that occur during the implementation of the project must be reported

immediately to the Chair of the C-REC.

Feedback regarding any adverse and unexpected events * Any adverse (undesirable and unintended) and unexpected events that occur during the implementation of the project must be reported to the Chair of the Social Sciences C-REC. In the event of a serious adverse event, research must be stopped immediately and the Chair alerted within 24 hours of the occurrence.

23/4/2014

APPENDIX 3: Online Survey - Acquired Brain Injury: The lived experience of relatives and friends

Introduction

This survey is being undertaken to find out the views and experiences of people who have a close relative or friend who has had an acquired brain injury. The results of this survey will be used to form research into these experiences from the family/friend perspective.

The intention and aim of undertaking this research is to inform services and professionals more clearly about the experiences of relatives and friends, and improve the response given to brain-injured people and their families.

The researcher will also be carrying out face-to-face interviews with a small group of relatives/friends who agree to be contacted.

The answers you give are entirely confidential. You will not be contacted by the researcher or any other party, EXCEPT if you state that you would like to be interviewed face-to-face AND you provide your contact details. You do not have to agree to this and so can stay entirely anonymous if you wish.

The survey has been approved by Sussex University Ethics Committee. If you have any comments or concerns regarding this survey and associated research please contact Dr Orr of University of Sussex, School of Education & Social Work, Brighton, BN1 9RH, Tel: 01273 678167 or at D.Orr@sussex.ac.uk

The survey consists of multiple choice questions and space for you to provide more information but only if you want to.

Thank you for participating in this survey; your time is very much appreciated.

Confirmation of Eligibility

This survey is designed to be completed by adults, resident in the UK who have a brain-injured relative/friend who were injured at least two years ago.

I confirm that I am:

- Over 18 years of age
- A UK resident
- A relative/friend of a person who had a brain injury 2 years or more ago

Yes ☐

No ☐

Information about you and your relative/friend*1. What is your age?*18 to 24 ☐25 to 34 ☐35 to 44 ☐45 to 54 ☐55 to 64 ☐65 to 74 ☐75 or older ☐

*2. What is your gender?*Male ☐Female ☐

3. What is your relationship with the injured party?

I am the...

Parent ☐Grandparent ☐Partner ☐Spouse ☐Brother ☐Sister ☐Child of ☐Friend ☐Other – please state below ☐

4. What is the injured person's age now?

11 to 18 ☐

19 to 25 ☐

26 to 35 ☐

36 to 50 ☐

51 to 65 ☐

65 or older ☐

5. Injured person's gender?

Male ☐

Female ☐

6. How long ago were they injured?

2 – 5 years ☐

6 – 10 years ☐

10 years plus ☐

7. How did they acquire their brain injury?

Road Traffic Accident (RTA) as driver/passenger ☐

RTA as pedestrian ☐

RTA as cyclist/motocyclist ☐

Assault ☐

Stroke/Brain Haemorrhage ☐

Viral illness such as meningitis/encephalitis ☐

Other – please state below ☐

--

8. Do you live with the injured person? If not, please state where they live.

They live in their own accommodation, alone ☐

They live in their own accommodation with family/partner/friends ☐

They live in their own accommodation with support ☐

They live in a rehabilitation unit ☐

They live in a residential/nursing home ☐

Other – please state below ☐

9. Does the injured person work?

Part-time open market ☐

Sheltered employment ☐

Voluntary work ☐

No, does not work ☐

Other – please state below ☐

What are the difficulties and challenges your relative has as a consequence of their brain injury?

People who have brain injuries can experience a range of difficulties, each person is different. The following set of questions aims to identify what particular difficulties your relative has.

Does your relative/friend have any of the following difficulties as a result of their brain injury?

'Executive' difficulties:

Some brain-injured people have difficulties with what are called 'executive' functions, such as:

- The ability to plan and organise
- The ability to prioritise
- To be able to carry out a plan
- To problem solve effectively
- To make decisions
- To be able to be flexible

11. Does your relative/friend have executive difficulties?

Yes ☐

No ☐

Don't know ☐

If you answered "Yes" to your relative/friend having executive difficulties, please rate on a difficulty scale of 1 to 10, where 1 is very little difficulty and 10 is extreme difficulty.

'Behavioural' difficulties:

Some brain-injured people have difficulties with their behaviour, for example, being unable to stop themselves from being impulsive or aggressive, or being passive or obsessive etc.

12. Does your relative/friend have behavioural difficulties?

Yes ☐

No ☐

Don't know ☐

If you answered "Yes" to your relative/friend having behavioural difficulties, please rate on a difficulty scale of 1 to 10, where 1 is very little difficulty and 10 is extreme difficulty.

'Emotional' difficulties:

Some brain-injured people have difficulties with their emotions, being depressed, anxious, having mood swings, being angry or not being able to care for other people and their points of view.

13. Does your relative/friend have emotional difficulties?

Yes ☐

No ☐

Don't know ☐

If you answered "Yes" to your relative/friend having emotional difficulties, please rate on a difficulty scale of 1 to 10, where 1 is very little difficulty and 10 is extreme difficulty.

'Physical' disability:

Some brain-injured people have difficulty with their physical abilities, such as being able to get in and out of bed independently, being able to stand, to walk, to dress themselves etc.

14. Does your relative/friend have physical difficulties?

Yes ☐

No ☐

Don't know ☐

If you answered "Yes" to your relative/friend having physical difficulties, please rate on a difficulty scale of 1 to 10, where 1 is very little difficulty and 10 is extreme difficulty.

'Sensory' impairment:

Some brain-injured people have difficulties with loss of sight, hearing, sense of touch, taste or smell.

15. Does your relative/friend have sensory difficulties?

Yes ☐

No ☐

Don't know ☐

If you answered "Yes" to your relative/friend having sensory difficulties, please rate on a difficulty scale of 1 to 10, where 1 is very little difficulty and 10 is extreme difficulty.

'Cognitive' difficulties:

Some brain-injured people have difficulties with their memory, their ability to concentrate, their ability to multi-task and their ability to think quickly, for example.

16. Does your relative/friend have cognitive difficulties?

Yes ☐

No ☐

Don't know ☐

If you answered "Yes" to your relative/friend having cognitive difficulties, please rate on a difficulty scale of 1 to 10, where 1 is very little difficulty and 10 is extreme difficulty.

'Insight'

Some people who have a brain injury do not have "insight" into their condition. This means that they are not always fully aware of the changes that have occurred to them as a consequence of their injury. This can mean that the brain-injured person cannot see what help they may need, may not believe they need any help or may recognise that they need help but not recognise this at the time the help is actually required.

17. Does your relative/friend have difficulties with loss of insight?

Yes ☐

No ☐

Don't know ☐

If you answered "Yes" to your relative/friend having insight difficulties, please rate on a difficulty scale of 1 to 10, where 1 is very little difficulty and 10 is extreme difficulty.

Social and relationship changes following brain injury

18. How has your relationship been affected by the brain injury?

19. Compared to before the brain injury, does your brain-injured relative/friend now have:

More Friends and social activities ☐

About the same number of friends and social activities ☐

Fewer friends and social activities ☐

20. Compared to before the brain injury, do you now have:

More Friends and social activities ☐

About the same number of friends and social activities ☐

Fewer friends and social activities ☐

Following a brain injury, you and/or your injured relative/friend may have used a number of different services. The following questions ask you to note which ones have been used, and your opinion of them.

21. Which, if any, of these services have you or your relative/friend used in relation to brain injury?

If you tick Yes, please use a scale of 1 – 10 to rate the service, where 1 is Excellent and 10 is extremely poor.

	Yes	If Yes, please rate according to the scale	No	Not Sure
Hospital (accident and emergency, intensive care, high dependency unit or neurosurgical unit)				
Inpatient rehabilitation (either NHS or other provider - if other provider please use 'other' option below to specify who the provider was/is)				
Social Worker/Social services				
Home care or support work services				
Day centre				
Brain Injury Case Manager				
Neuropsychologist/psychologist				
Physiotherapist				
Occupational Therapist				
Speech and Language Therapist				
Neuropsychiatrist/Psychiatrist				
Counsellor				
Support service such as Headway or CBIT				
Other: 1				
Other: 2				
Other: 3				

If you selected 'Other: 1, 2 or 3' above, please note each service you accessed. If you accessed more than three 'Other' services please use the space below to detail what they were and rate them as per the above scale.

Your experience of services relating to brain injury

The following questions allow you the opportunity to describe your experiences in more detail and to note where you feel improvements could be made. None of these questions is compulsory but your personal experience and story is valuable for this survey.

All brain-injured people and their families are individual and whilst some experiences will be the same, some will not. A survey cannot hope to capture all of that detail and so space has been provided for you to add more information if you wish. All of your comments will be welcomed.

22. How well did these services include you and your knowledge/experience of the brain injured party in their work? Thinking about the services you have used, what is the one thing that could have been done differently that would have improved your experience?

23. How well did these services include you and your knowledge/experience of the brain injured party in their work? Thinking about the services you have used, what is the one thing that could have been done differently that would have improved your experience?

24. Were you given the information you needed to understand brain injury and services?

25. Were you given the information you needed to understand brain injury and services?

26. What are the three most difficult things that you face now as a relative/friend of a brain-injured person, and how well have you been supported to face these?

27. What are the three most difficult things that you face now as a relative/friend of a brain-injured person, and how well have you been supported to face these?

28. Knowing what you know now, what would you do differently if you could go back to the time when your relative/friend was first injured?

Please use the space below to provide more information regarding the changes and difficulties that you and your relative/friend face. What would you suggest professionals need to do to improve the services provided?

30. Would you like to take part in one-to-one interviews?

In order to obtain more in-depth information about specific aspects of the relative/friend's experience of brain injury direct one-to-one interviews are planned with the researcher and family members.

The one-to-one interviews are likely to last between one and two hours, will be recorded if you give permission and will take place at a private place of your choosing. This could be your own home or elsewhere. The person conducting the interviews is an experienced professional within the field of brain injury, has been CRB checked and will carry documentation to prove their identity. The information given to the researcher will remain anonymous.

If you are happy to be contacted by the researcher, please provide either or both your email address and telephone number. Please note how you would prefer to be contacted. If you provide a telephone number please note if there are any times you do not wish to be called or if you have any other instructions as to how you would like to be called/when.

Email address	
Telephone number	
Contact preference/times	

Thank you for your contribution to this survey, it is greatly appreciated and will hopefully form part of supporting future improvements to services for brain injured people and their families.

Sources of support available to relatives and friends of brain injured people:

If you wish to access information and support with any of the issues addressed in this survey, the following sources of assistance may be helpful.

1) Headway

This is the national charity for people who have had a brain injury and their family members. Headway can help you in a number of ways, these include:

A free helpline 0808 8002244

The website www.headway.org.uk

Headway has local groups that meet and provide support for the relatives of brain injured people, have a wealth of factsheets and knowledge and can provide advice if you need assistance.

2) Child Brain Injury Trust (CBIT)

This is a national charity for parents of children who have suffered a brain injury. CBIT can help in a number of ways, these include:

A national helpline 0303 303 2248

<http://childbraininjurytrust.org.uk>

CBIT has local support groups, factsheets and training events aimed at supporting parents with a brain injured child.

3) Your GP

If you feel unwell or unable to cope with the demands made upon you as a relative of a person with a brain injury, please tell your GP.

4) Social Services

You and your brain injured relative are entitled to an assessment of your needs by a social worker. It is possible, subject to assessment that services may be provided directly to you or via a cash payment so you may arrange the services yourself. It may be advisable to speak to your local Headway first as they will have direct experience of the local authority in your area.

APPENDIX 4: Letter to interviewees



29th September 2014

Ms _____

Dear _____

RE: RESEARCH: THE VIEW OF RELATIVES OF PEOPLE WITH A BRAIN INJURY

Thank you so much for agreeing to be interviewed by me. I remain very grateful for your time and commitment.

I am lucky to have heard back from all 16 individuals that I wish to interview, each kindly also in agreement, and now I am in the process of trying to arrange dates to visit everybody. As people are spread all over the country this has proved to be quite a challenge but I am hopeful that I have managed to at least make a good start on this process.

I wondered whether the following date and time would suit you?

Thursday 11th December 2014 10am

I would anticipate that the interview would last approximately between one and two hours and would want to ensure that this fits in with your other commitments so that you feel able to speak freely about your experience.

Can you please let me know if this date and time suits you? You may do this by email or telephone, whichever is best for you on 07779657338 or mark.holloway@head-first.org

If you have any questions or concerns about this process please do not hesitate to contact me.

Yours sincerely

Mark Holloway DipSW MA
Brain Injury Case Manager and Doctoral Researcher

Grove Mills, Cranbrook Road, Hawkhurst, Cranbrook, Kent TN18 4AS
Tel: 01580 752275 Fax: 01580 754475 www.head-first.org
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APPENDIX 5: Breakdown of nodes

Mother Node	Daughter Node	Granddaughter Node	Number of sources	Number of references
ABI related needs and changes			16	126
	Difficult behaviour		16	98
		Behaviour in the community	14	78
		Insight and difficult behaviour	12	43
	Difficult to engage		8	17
	Long term nature of needs		13	32
	Mental health adaptation		8	33
	Need for family input		14	164
	Positive changes		9	27
	Risks (early days)		6	13
	Serious needs missed		6	12
	Time without support or knowledge		9	22
	Invisible difficulties		13	83
	Vulnerability		10	52
	What worked		6	15
Family need and emotions			13	33
	Acceptance of change/growth		10	24
	Ambivalence, guilt and hope		14	114
		Better off dead	7	16
	Burden of care		16	154
		Burden of fighting	5	14
		No option, taking responsibility	11	38
	Change in relationship /relationships		13	29
	Coping strategies		15	110
		Learning about ABI	14	45
		Peer support	10	25
	Early days, family coping		11	24

	Fears for the future		12	38
		Hope for the future	10	23
	Grief, ambiguous loss		12	97
	Impact on children or siblings		8	68
	Losses		12	47
	Need to allow change and services to work		5	10
	Other issues to contend with		15	80
	Positive input to ABI		10	32
	Positive relationship, changes or experiences		8	23
	Pre-injury situation		5	14
	Respondent lack of knowledge		12	24
		Other family lack of knowledge	1	5
		Respondent prior knowledge	4	9
	Value of family knowledge		6	13
	What would happen without the relative		9	17
		To be done differently or advice given	5	11
Finding out about the accident/injury			16	57
Input from professionals, negative			3	5
	Ambivalent feelings about need for services		10	32
	Complaining, fighting, bureaucracy, funding		9	59
	Hearing bad news		6	7
	Improving professionals		14	39
	Need for input		5	7
		Need for continuity	7	16

	Negative experience of professionals		10	30
		Lack of understanding	16	86
		Not accessing rights services or service not doing what it needs to	16	104
		Not fitting criteria or service not available	15	45
		Not taking responsibility or blaming confidentiality	8	26
		Poor attitude of professionals	8	25
		Poor communication, no information	13	50
		Professional lack of knowledge of insight and executive impairment issues	7	34
	Negative hospital experience		13	32
		Bad discharge	11	19
		Not being followed up	8	15
		Not being informed about the brain injury	7	15
		Possible hospital negligence	4	16
	Not involving or believing family		7	21
Positive input from professionals			15	91
	Positive hospital experience		7	13
	Good communication		11	30
	Headway or charity		12	38
	Involving client or family		5	15
	Knowledgeable professionals		9	20
	Positive attitude		14	48
	Professional goes beyond role		12	33

	or involves family outside of norm			
	Professional understands lack of insight	1	2	
	The right support, continuity	9	61	
Litigation		0	0	
	Negative impact of litigation	6	42	
	Positive impact of litigation	3	8	
Other people		14	110	
	Not telling others	12	32	
	Other ABI people	5	12	
	Other family members	16	111	
	Support from others	11	33	
OTHER		0	0	
	Background	6	20	
	Info exchange	8	13	
	Pre-accident functioning	2	2	
	Pre-amble	7	7	
	Relationship development	5	12	

89 Nodes

8 Mother Nodes

58 Daughter nodes

23 Granddaughter nodes

APPENDIX 6: Prompts for interviewer:

The following questions were available on a “prompt sheet” for the interviewer and were referred to if required.

1. What was the impact and facts surrounding the initial event, when you heard about the accident/occurrence of the brain injury?
2. What is the “story” of the initial days in the more intensive hospital settings, the feelings evoked by interaction with staff and the beliefs/hopes/fears held by you?
3. What was your experience at the point post discharge/post acute health crisis?
4. What is your experience of accessing services?
5. What is your experience of changes to friendships, opportunities, finances, connection with the wider world, etc?
6. Describe life today. What is different? How do you negotiate changed roles?
7. What has worked for you? What do good services do well? What do you do to help you get through the day/week?
8. What would you tell someone who found their loved one newly brain injured, what have they learnt that others would benefit from?

APPENDIX 7: Consent form**PROJECT TITLE: Acquired Brain Injury: The lived experience of family members.****CONSENT FORM:**

Key contact (researcher): Mark Holloway, University of Sussex, Falmer, Brighton BN1 9QQ Tel: 01580 752275; Email: mh373@sussex.ac.uk

Research supervisor: Dr David Orr, University of Sussex, Falmer, Brighton, BN1 9QQ, Tel: 01273 876648; Email: D.Orr@sussex.ac.uk

Thank you for considering taking part in this research. The researcher (Mark Holloway) will discuss the details of the information sheet and consent form with you, and will answer any questions you may have. If anything is not clear, please ask. You will be given a copy of this consent form and an information sheet to keep so you can refer to them at any time.

Please read the statements below and indicate your answer.

- | | | | |
|---|---|------------------------------|-----------------------------|
| 1 | I agree to take part in the above research project. I have read and understood the information sheets and I have had the opportunity to ask questions, which have been answered satisfactorily. | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| 2 | I understand that my participation is voluntary, that I can choose not to participate in part or all of the discussion, and that I can withdraw at any stage without being penalised or disadvantaged in any way. | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| 3 | I understand that the information I provide is confidential, unless it appears that either I or a vulnerable third party is at risk and appropriate measures are not being taken. | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| 4 | I understand that what I say may be used in the research report, but that no name or details will be given from which I could be identified. | YES <input type="checkbox"/> | NO <input type="checkbox"/> |
| 5 | I understand that my personal information will be kept confidential and will be stored securely. It will only be used for the purposes of this research study and it will be destroyed when the study is over. | YES <input type="checkbox"/> | NO <input type="checkbox"/> |

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- 6 I agree to allow the interview to be audio-recorded, for the sole use of the researcher Mark Holloway, and that the recording will be kept securely and destroyed at the end of the project.

YES

☐

NO

☐

Name of participant (please print):

Signature of participant:

Date:

Name of researcher (please print):

Signature of researcher:

Date:

APPENDIX 8: Information for participants

INFORMATION SHEET

Acquired Brain Injury: The lived experience of family members.

1. What are the interviews for?

The idea of the interview is to allow you to tell your story, to gain a greater understanding of your experience and knowledge as the relative/friend of someone with an acquired brain injury. The interview should allow you the opportunity to describe the changes brought about by the brain injury suffered by your friend/relative, how this has impacted upon you both and the wider family and what your impression is, good and bad, of the services and professionals you have encountered since.

2. What will I be asked?

This really depends upon what you wish to discuss but the intention is that rather than answering a list of prepared questions, the interview should permit you to discuss in detail your very individual experience.

3. This is personal information, how do I know that my answers are going to be kept confidential?

This is very important. The answers you give will be recorded on a digital recorder and the interview will be transcribed and inputted in to a secure computer with your name and any identifying details removed. There is no way of identifying who gave which answers.

Nobody apart from the researcher, Mark Holloway, will see your personal information. Recordings and notes will be kept until the research is complete and then destroyed. The only time your confidentiality would not be kept would be if it became apparent that you and/or the brain injured person was at serious risk of harm in which case I would be duty bound to inform the relevant authorities.

4. Who is Mark Holloway?

I am a senior brain injury case manager who has worked with brain injured people and their families since 1991. I am also a doctoral student at Sussex University and this research is part of a research project I am undertaking to improve services.

5. Why does Mark Holloway want to know about my experience?

Having spent over 20 years working with brain injured people and their families I am interested to learn more about the family members' experience. This is important because this learning can be used to improve services for brain-injured people.

6. Where will the interview take place and how long will it last?

The location depends upon your choice but this will most likely take place at your home or a private venue of your choosing. The interview is estimated to take between an hour and two hours and so it will be important that we plan a time that suits you best when we can have fewest disruptions.

7. What will happen if I say that I do not want to take part?

Nothing at all. It is your choice whether to take part or not. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

8. What are the possible risks and disadvantages of taking part?

For most people the experience of having a loved one suffer a brain injury is an upsetting and unwelcome life-changing event. Talking about this event and the aftermath, in depth, may act to remind you of this time and so can be an emotional experience. To limit the negative impact of this you will be provided with documentation and contact details for organisations that are established to help the relatives of brain injured people.

9. What are the possible benefits for me?

You are the expert on your life and your experience. If you participate then you can be part of teaching professionals to become better at their jobs, helping to improve the quality of the responses given to brain injured people and their families. Some people also find that being given time to discuss their experiences is helpful.

10. Why do I have to sign a consent form?

It is very important that we recognise that it is you who decides whether to take part or not. The University has very strict rules to protect participants in research and rightly insist that nobody is forced to do so. By having a signed record, the University can be assured that this is the case.

11. What will happen to the information I give?

Your answers are entirely confidential and service providers will not be given direct feedback regarding what you have said about them, good or bad. The findings from the research will be written up in a doctoral thesis and articles to inform professionals who work with brain injured people and their families to improve their practice.

12. Who has approved this study?

This study has been approved by the University of Sussex Ethics Committee.

13. Where can I find more information about this?

There are a number of ways to find out more information. You can:

- Email me (mark.holloway@head-first.org)
- Call me during office hours on 1580 752275
- Call or email my supervisor at Sussex University Dr David Orr, University of Sussex, School of Education & Social Work, Tel: 01273 678167; d.orr@sussex.ac.uk

Thank you for taking the time to read this information sheet.

Mark Holloway